

Primary Appraisal Antiretroviral Adherence and Nonadherence among People Living with HIV (PLWH)

Widia Shofa Ilmiah¹, Stefanus Supriyanto², Purwati³, Mochammad Bagus Qomaruddin²

¹Student of Doctoral Programme of Health Science, Faculty of Public Health, Universitas Airlangga, Mulyosari Street, Surabaya, Indonesia; ²Lecturer of Faculty of Public Health, Universitas Airlangga, Mulyorejo Street, Surabaya, Indonesia; ³Lecturer of Faculty of Medicine, Universitas Airlangga, Moestopo Street, Surabaya, Indonesia

ABSTRACT

HIV is an iceberg phenomenon that still needs a problem solving. The data from the voluntary counselling and testing in Waluyoajati General Hospital show that every month about 8-15 new people got HIV infection and Antiretroviral Therapy. Some of them adhered to undergo ARV, but some did not. One of influential factors for adherence to ARV is individual factor which consists of primary appraisal includes perceived susceptibility, severity, benefit, barrier and motivational relevance and secondary appraisal includes self-efficacy, perceived control outcome and emotion, and external factors. The aim of this study is to describe primary appraisal of antiretroviral adherence and nonadherence among People Living With HIV (PLWH). This study is a qualitative study using a content analysis. This study carried out in-depth interviews with 10 PLWH who received ART for about two weeks – three months. The results show that non adherence to ART is caused by several factors, such as income, perceived susceptibility, perceived severity, perceived barriers. Some of non adherence patients are bored to taking ARV every day and get several side effects, such as nausea and vomiting, erythema, HIV disclosure, fear of stigma. Both patients who adhere and do not to ARV perceived that taking ARV makes them healthy, resistant to be tired, less anxious or hospital care costs, and motivated like people with no HIV infection. Patients who do not adhere to ARV have more perceived barrier than perceived benefit and motivational relevance.

Keywords: Primary Appraisal, Antiretroviral, Patient, Adherence, HIV

Introduction

HIV not only attacks the key population, but also has spread to general communities.¹ A treatment to address HIV cases can be given by giving Antiretroviral therapy (ARV).¹

According to World Health Organization in 2016, there were 36.7 million PLWH;² whereas in Bali, Indonesia from 1987 to December 2016, about 80% of

its population got HIV AIDS and had spread to 80.2% of districts and cities. According to provinces, East Java province has the third highest number of HIV infections (0.08%). The cumulative HIV cases in Probolinggo district from 2012 to 2017 happened to 1,072 people (1%).³

A preliminary study conducted in the VCT Clinic of Waluyoajati General Hospital. The researchers interviewed medical record staffs. It was found that in 2018, the cumulative number of HIV AIDS cases occurred to 1,140 people, and every month about 8-15 new people suffered from HIV infection. Seventy-five percent of them were qualified for ARV treatment, and a quarter of them had not received ARV treatment. From 75% of 10% lost to follow-up ARV, and 59.6% are active on ARV treatment.³ It indicates that some patients do not adhere to the ARV treatment based on doctor's instructions.

Corresponding Author:

Widia Shofa Ilmiah
Student of Doctoral Programme of Health Science,
Faculty of Public Health, Universitas Airlangga,
Mulyosari Street, Surabaya, Indonesia
Email: widiailmiah86@gmail.com
widia.ofa.ilmiah-2016@fkm.unair.ac.id

Multi-factors that caused non adherence to ARV include beliefs and self-efficacy.⁴ Meanwhile, according to other researchers that adherence barriers are caused by lack of knowledge and motivation, alcohol addiction, unavailability of food, stigma, disclosure of HIV status, the number of pills taken by patients.⁵ Other factors of nonadherence are caused by social support, family or parent support, knowledge about a disease, self-motivation, beliefs about positive results.⁶ Other results of the preliminary study show nonadherence is also caused by stigma, disclosure, lack of support from her partner, transportation expense, side effects, service waiting time.⁵

The aim of this study is to describe the primary appraisal of antiretroviral adherence and non adherence among people living with HIV.

Materials and Method

This qualitative study was conducted to patients in the VCT Clinic of Waluyoajati General Hospital, Probolinggo Distric. The number of patients undergoing an ART about 2 weeks-3 months in Februari 2018. Ten participants were selected as samples. Five patients and the others do not adhere to the ART. Based on the inclusion criteria, the respondents involve females living with HIV aged more than 15 years old in Probolinggo District. Patients who are still on TB treatment are excluded to be respondents.

Respondents who agreed to participate in this study signed a written informed consent. The researchers uses a close ended questionnaire to identify the characteristics of patients and an interview guide using fourteen open questionnaires to identify knowledge about ARV, perceived susceptibility, perceived severity, benefit, barrier, and motivational relevance, uses audio recorder after getting respondents' consent. Respondents speak Indonesian or local language (Javanese/Madurese). Each interview lasted about 20-30 minutes. All respondents' profiles were anonymous during the data transcription. The analysis was done manually by using a content analysis. The transcriptions were read for 3-4 times to identify all key ideas and current themes.

Findings

Sociodemographic Characteristics: Ten females living with HIV are 23 years old up to 50 years old. Based on education level, seven respondents went to elementary

school, two respondents graduated from senior high school and 1 respondent from a college. In terms of salary, one respondent has no fixed income, four people earn < Rp.500,000,-, four people gain Rp. 500,000,- and one person earn Rp. > 500,000,- each month. Nine of the respondents are house wife, and one respondent is entrepreneur. Two of them are Javanese, and eight respondents are Madurese.

Patient's Knowledge: The majority of respondents (five respondents who adhere and two who do not) have good knowledge about the side effects of ARV, problem solving, condition in taking ARV, time schedule to take ARV, impacts of unregular ARV therapy. However, almost of all respondents (four respondents who adhere and five respondents who do not) have bad knowledge about what ARV medicine is and objectives of taking ARV.

ARV medicine can prevent HIV in order to have healthy body and long life For the side effects, I'll go to a doctor...drinking every day in the same time, if not.. we will be sick...

(SR, 42, patient who adhere to ARV)

ARV medicine can fight the HIV to recover my body quickly... (HN, 35, patient who do not adhere to ARV).

Perceived Susceptibility Factors Affecting Adherence:

In terms of perceived susceptibility of patients about ARV, three respondents (one respondent who adhere and two respondents who do not adhere) are bored for taking ARV every day. On the other hand, seven respondents (2 respondents who adhere and five respondents who do not adhere) sometimes forget to take it on time.

Nothing..i did not forget...no difficulties.. (SC, 27, respondent who adhere to ARV).

I am bored for taking medicine continuously forever. Furthermore, taking ARV should be on time (PA, 27, respondent who do not adhere to ARV)

Perceived Severity Factors Affecting Adherence:

In terms of perceived severity, eight respondents (three respondents who adhere and 5 respondents who do not adhere to ARV) stated that severity is caused by patient's susceptibility.

Not too disturbing anyway...I can afford to solve it (HU, 44, respondent who adhere to ARV)

Quite annoying...I often forget...quickly got sick...like headaches...nausea...tired...often sleepy (IK, 32, respondent who do not adhere to ARV)

Being healthy...can work...if I were healthy, they would not believe that I am HIV sufferer. They believe that PLWH are thin...I still look healthy (JT, 23, respondent who do not adhere to ARV)

Perceived Benefit Factors Affecting Adherence: All respondents have benefit for taking ARV. This statement was captured in the below:

The benefit is to make my body healthy, so my activity goes well...(LS, 36, respondent who adhere to ARV)

Yes... sometimes my body felt fresher after taking ARV...I am more diligent to work... Like healthy people in general, they will not believe if I am HIV (JT, 23, respondent who do not adhere to ARV)

Perceived Barrier Factors Affecting Adherence: Six respondents (two people who adhere and four people who do not) mentioned that the side effect of ARV is the barrier. Two respondents said that another barrier is inadequate income (one respondent who adhere and one respondent who does not adhere). Two respondents who adhere to ARV do not have any barrier to take ARV. All respondents took ARV unless someone will disclose their HIV status.

After taking ARV especially in the first week, I feel nausea, vomiting... Furthermore, I sometimes got headaches...(SR, 42, respondent who adhere to ARV)

Because of high transport fares and financial constraints. I do not have health insurance, so I do not take ARV...I have been drinking coconut oil herbal ...drinking zaitun oil and eating more (IK, 32, respondent who do not adhere to ARV)

I am too busy to regularly take ARV., If I remember, I will take it soon (HU, 44, respondent who adhere to ARV)

Motivational Relevance Factors Affecting Adherence: Seen from the motivational relevance of taking ARV, ten patients said that they want to be normal people who do not get HIV infection, can work normally, have healthy body, do not get stigma from society, and have long life.

My motivation on taking ARV therapy is because I want to be like others who do not get HIV infection and work normally...being healthy...no stigma from neighbours (SR, 42, respondent who adhere to ARV)

Discussion

Sociodemographic Characteristics: In this study, all respondents have lower income than minimum regional salary. They have financial constraints, so they are unable to spend enough money for transport, take their medication as prescribed.

Adherence is a form of behavior arisen from the interaction between a doctor and a patient, so they understand, approve, and execute their plans and consequences.⁹ Multi-factors that affect to adherence include communication, social-economy, employment, level of knowledge about treatment, medical insurance, basic health services, and ethnics.¹⁰

A patient with low income has more difficulties of adherence.⁸ Even though ARV medication is freely provided in Indonesia, but unemployment, transportation cost, and ownership of health insurance still affect patients to take ARV. Additionally, education level does not always get associated with adherence. In this study, five respondents who do not adhere to ARV went to elementary school, high school and college. According to the study done by Hanif, socio-demographic like education level does not get consistently associated with adherence.¹¹

Patient's Knowledge: The majority of respondents have good knowledge about side effects, problem solving, condition in taking ARV, schedule for taking ARV, impact due to unregular ARV therapy. However, almost all respondents do not know what ARV medicine is and the objectives of this medication.

Knowledge is the results of knowing after someone conducts or senses something or a particular object.¹² This is consistent with Van Dyk who mentions that maintenance group is patients who understand about ARV. In the contrary, nonadherence group is patients who lack knowledge about ARV and have missing meaning about ARV. The ARV therapy does not function to fight HIV, but it only suppresses the progression of HIV.¹³

Perceived Susceptibility Factors Affecting Adherence: The majority of patients in this study have perceived

susceptibility. They feel bored for taking ARV every day and sometimes forget to take it on time.

Perceived susceptibility is one of the powerful beliefs to prompt people to adopt healthier behavior.¹⁵ It can be seen that a belief of increased susceptibility or risk is associated with healthier behavior and decrease susceptibility to unhealthy behavior.¹⁴ Perceived susceptibility about ARV and HIV disease is related. Denial of HIV status as identified needs to be addressed through intervention in order to accept HIV status, and the implication of the diagnosis will give patients clues to take ART.⁷

Perceived Severity Factors Affecting Adherence: In this study, most of respondents argued that severity is caused by susceptibility that patients experience. Perceived severity is an individual belief in disease severity or the needs of ARV medication according to doctor instructions.¹⁶ Perceived severity will make patients stressed if they do not have a good self-efficacy. It is evidenced that patients who have perceived severity can cope the mechanism and adherence to ARV therapy. Respondents who do not have severity will adhere to take ARV.¹⁵

Perceived Benefit Factors Affecting Adherence: All respondents in this study have benefits after taking ARV. Some of them do not have a good perceived benefits for taking ARV, but a half of them have a high level of adherence.

Perceived benefit is an individual belief about the efficacy and feasibility of particular actions to treat and prevent a disease or to take ARV medication according to doctor's instructions.¹⁷ Some studies show that good perceived benefits are related to patients' adherence. Patient's belief in ARV benefits have been correlated with ARV adherence. Moreover, perceived effectiveness of ART is related to ARV adherence.¹⁷

Perceived Barrier Factors Affecting Adherence: This study shows that the majority of respondents considered side effects as barriers of ARV adherence. Moreover, since they work, it is hard to hide their HIV status. Only few had no barriers.

Perceived barrier is individual belief in things that inhibit ARV adherence.¹ Barriers give negative impacts on social and worklife, secrecy and stigma.¹³ Furthermore, many patients hide their HIV status

because they are afraid of stigma which becomes a major barrier to change. It may be an important reason for why many patients take ARV on time or late.⁶

Motivational Relevance Factors Affecting Adherence: All respondents in this study want to become normal people who can work normally, live healthily get no stigma from society, have a good immune system and long life.

Motivation is a part of primary appraisals in *Transactional Model of Stress and Coping Theory*. Motivational relevance is an individual belief to do something.¹⁷ People who have motivational relevance can cope their problems in taking ARV and decide whether or not to adhere. Autonomous motivation is strongly associated with perceived competence and correlated with adherence.¹⁸

Conclusions

In conclusion, education level, employment, and ethnics do not always affect adherence, but income is significantly. Knowledge about ARV therapy, perceived susceptibility, perceived severity, perceived benefit, perceived barrier, and motivational relevance affect adherence to ARV as well. Moreover, self-efficacy, controlled outcome, controlled emotion, cues to action and others influence patients' adherence to ARV therapy.

Conflict of Interest: This study didn't have conflict of interest with General Hospital that become location of this study.

Source of Funding: This study have self findings by the authors.

Ethical Clearance: Prior to the research, an ethical approval was conducted by a reviewer of Health Science of Hafshawaty Pesantren (Islamic Boarding School) Zainul Hasan Probolinggo, East Java, Indonesia.

REFERENCES

1. Directorate General of disease control and environmental health. *Statistics of HIV AIDS in indonesia*, Health Ministry 2017, <http://spiritia.or.id/Stats/detailstat.php?no.8>, Citation date 14 June 2017.
2. WHO. *10 Fact on HIV/AIDS*, <http://www.who.int/features/factfiles/hiv/en/>, citation date 13 June 2017. 2016.

3. Clinic VCT of General Hospital Waluyoajati. *Data of HIV AIDS Case 2012-2018 and Antiretroviral Treatment Terapi ARV in Clinic VCT General Hospital Waluyoajati*, General Hospital. Probolinggo. 2018.
4. Ilmiah W S, Qommaruddin M B, Putri S.U, Iswardani N. Belief, Self Efficacy And Other Predictors Of Adherence To Art Among Women Live With Hiv. *Proceeding 2nd Symp Public Health*. 2017;2(1):610–5.
5. Lyimo RA, De Bruin M, Van Den Boogaard J, Hospers HJ, Van Der Ven A, Mushi D. Determinants of antiretroviral therapy adherence in northern Tanzania: A comprehensive picture from the patient perspective. *BMC Public Health*. 2012;12(1).
6. Ankrah DNA, Koster ES, Mantel-Teeuwisse AK, Arhinful DK, Agyepong IA, Lartey M. Facilitators and barriers to antiretroviral therapy adherence among adolescents in Ghana. *Patient Prefer Adherence*. 2016;10:329–37.
7. Nalugoda F, Chang LW, Kanya M, Nakyanjo N, Kigozi G, Makumbi FE, et al. A Qualitative Study of Barriers to Enrollment into Free HIV Care: Perspectives of Never-in-Care HIV-Positive Patients and Providers in Rakai, Uganda. *Biomed Res Int*. 2013;2013:1–7.
8. Letta S, Demissie A, Oljira L, Dessie Y. Factors associated with adherence to Antiretroviral Therapy (ART) among adult people living with HIV and attending their clinical care, Eastern Ethiopia HIV/AIDS. *BMC Int Health Hum Rights* [Internet]. 2015;15(1):1–7. Available from: <http://dx.doi.org/10.1186/s12914-015-0071-x>
9. Health Ministry. *Antiretroviral treatment Guidelines*. Health Ministry. Jakarta. 2014.
10. Willard S, Angelino A. The need for sociocultural awareness to maximize treatment acceptance and adherence in individuals Initiating HIV therapy. *J Int Assoc Physicians AIDS Care*. 2008;7(SUPPL. 1):17–21.
11. Hanif H, Bastos FI, Malta M, Bertoni N, Surkan PJ, Winch PJ, et al. Individual and contextual factors of influence on adherence to antiretrovirals among people attending public clinics in Rio de Janeiro, Brazil. *BMC Public Health*. 2013;13(1).
12. Notoatmodjo, S. *Health behavior Sciences*. Nuhamedika. Yogyakarta. 2014.
13. Peltzer K, Friend-Du Preez N, Ramlagan S, Anderson J. Antiretroviral treatment adherence among HIV patients in KwaZulu-Natal, South Africa. *BMC Public Health*. 2010;10.
14. Rosenstock IM. The Health Belief Model and Preventive Health Behavior. *Monograph*. Vol. 2. 2014. pp: 354-386.
15. Glanz K, Rimer BK, Viswanath K. *Health Behavior and Health Education, Theory, Research and Practice*. 4th ed. Jossey Bass; 2008. pp:1-552.
16. Vitalis D. Predicting adherence to antiretroviral therapy among pregnant women in Guyana: Utility of the Health Belief Model. *Int J STD AIDS*. 2016;28(8):756–65.
17. Chan PY, Joseph MA, Jarlais DC Des, Uuskula A. Perceived effectiveness of antiretroviral therapy, self-rated health and treatment adherence among HIV-positive people who inject drugs in Estonia. *Int J STD AIDS*. 2017;0(0):1–10.
18. Vian T, Bachman DeSilva M, Cabral HJ, Williams GC, Gifford AL, Zhong L, et al. The role of motivation in predicting antiretroviral therapy adherence in China. *J Health Psychology* [Internet]. 2016;135910531667292. Available from: <http://journals.sagepub.com/doi/10.1177/1359105316672922>.