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Qualitative Study; Knowledge, Arv Access, and Adherence among People Living With HIV in Bulukumba District, South Sulawesi

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ABSTRACT

Background: HIV/AIDS is a complex problem that requiring active involvement of people living with HIV/AIDS (PLHIV) to control it. Knowledge about ARV access and adherence is essential for PLHIV to improve self-care behavior in seeking health services. This study aim was to obtain a description of knowledge, ARV access, and adherence among PLHIV in Bulukumba District.

Method: Qualitative study was conducted among 10 participant, consisting PLHIV, doctor, counsellor, The National AIDS *Commission* staff, peer support. Participant was identified by using Snowball sampling with Content analysis.

Result: The results of study provide a description which is most PLHIVs already know the basic information about Human immunodeficiency virus (HIV) Acquired immunodeficiency syndrome (AIDS), prefer to access ARV outside of Bulukumba district, and their reason of not adherence in treatment.

Conclusion: This result suggest to establish a place as a gathering of PLHA for sharing knowledge, mutual support, and reminding each other. Starting antiretroviral (ARV) and adherence are importance to maintain and improve their quality of life.

Keyword : HIV/AIDS, Knowledge, ARV Access, Adherence

INTRODUCTION

HIV/AIDS is one of seriously health problems and challenges in the world. Until now, there were 36.9 million PLHIV and 17.1 million were. 22 million of PLHIV did not get access to ARV therapy, including 1.8 million of children.^{1,2} Mathers and Loncar (2006) predicted the deaths due to HIV/AIDS will continue to increase in 2030.³

Ministry of Health (MoH) reported that HIV prevalence in Indonesia was 191,073 people and AIDS

cases were 77,112 people. The number of PLHIV who received ARV therapy is 63,066 people. This means that only about 33% of HIV patients who received ARV therapy.⁴ South Sulawesi is the second largest of HIV prevalence in eastern Indonesia and Bulukumba district is the third rank of HIV /AIDS prevalence in South Sulawesi.⁴ The risk factor of HIV transmission are heterosexual, IDU's, and pregnancy/breast feeding. Bulukumba hospital reported that number of PLHIV who started ARV is only 6.7% of HIV diagnosed.

Knowledge about ARV therapy is importance and dispensable for PLHIV. Lack of knowledge related to ARV therapy can make PLHIVs making wrong decisions about their treatment.^{5,6} Previous study reveals the quality of life among PLHIV can increase after ARV initiation. Additionally, adherence is also an important component in the success of ARV therapy and improve

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their quality of life. However, ARV access is still a polemic in developing countries.^{7,8} This study seeks to provide a description of knowledge, ARV access, and adherence of PLWHA in Bulukumba District,

METHOD

Qualitative study as conducted among 10 participants including PLHIV, doctor, counsellor The National AIDS *Commission* staff, and chairman of peer support NGO in Bulukumba district. Data were collected by using structured interview instruments in in-depth interview with PLHIV and Focus Group Discussion (FGD) with health officer. Snowball sampling was used to determine the sample. Data was analyzed by content analysis method. The steps on content analysis include; 1) Making a transcript, 2) determine the meaning unit, 3) summarizing and organize data, 4) performing data abstraction, 5) creating categories and theme compilations, 6) drawing a conclusion.

Ethics

This research has obtained Ethical Approval Recommendation Hasanuddin University Number: 547/H4.8.4.5.31/PP36-KOMETIK/2017

FINDINGS

Characteristic of participants

Total of 10 participants, consisting of 6 PLHIV with five male and one female, one of doctor, one of counsellor, one of The National AIDS *Commission* staff, and chairman of peer support NGO. Interviews with informants were formulated 3 themes, namely knowledge about basic HIV/AIDS information and its treatment, ARV access and adherence to ARV treatment.

Knowledge of HIV/AIDS

PLHIVs knowledge based on interview result as follows:

“HIV/AIDS is deadly disease, most feared by people because it can be transmitted through sex, needles, vertically from HIV-positive pregnant women to their babies and from breast milk. Prevention by not doing risky behavior, always trying to increase knowledge and treated with ARV treatment.

(PLHIV: SR, 33 years, AB, 27 years)

“HIV is a virus that destroys white blood

cells, incurable diseases and having negative stigma in society. It is transmitted through unsafe sex, sharing needles, and from mother to child. HIV can be prevented by not performing risky behavior and can be treated with ARV treatment”
(PLHIV: IK, 33 years)

Our study identified that most of PLHIV understood HIV is a virus which attacks white blood cells, a deadly disease and not healing if it were not treated, transmitted through needles, sex, drugs injection, and mother-to-child transmission. PLHIV considered that HIV is a deadly and feared disease but it can be prevented by increasing information and avoiding risk behavior of HIV transmission. They has known that ARV therapy is a treatment to maintain their quality of life.

ARV access

Interview results with PLHIV related to ARV access, as follows:

“.... Some PLHIV started ARV therapy in Makassar with consideration that safety, comfort, and confidentiality can be more secure compared start treatment in their district. They still do that although they have to spend money for their transportation “
(PLHIV: SR, 33 years)

“..... Actually, we have tried as much as possible to overcome the problem of ARV access at Bulukumba hospital, but PLHIV already started ARV therapy in Makassar did not want to move treatment at Bulukumba hospital. They feel more comfortable undergoing treatment in Makassar “
(Doctor: WW, 44 years)

“..... I often motivate friends to keep taking ARV Therapy even though the place of taking medicine is so far. It’s been one time Bulukumba hospital did not provide ARV regiment. So, there are some of PLHIV who were forced to move treatment in Makassar..... “
(Peer support: DL, 43 years)

Our interview identified that about there were 3 of participants accessing ARV treatment in Makassar (outside of Bulukumba district) and 3 others accessing ARV at Bulukumba hospital. They also said that ARV therapy were not difficult to obtain but transportation cost, consumption, and accommodation every month for who treated in Makassar incriminate participants.

Adherence

Interview results with PLHIV related to treatment adherence as follows:

“... personally, I try to drink ARV therapy on a dose and on time, but sometimes I have to stop taking the medicine when my ARV therapy runs.

(PLHIV: SR, 37 years)

Average of PLHIV adhere on treatment and sometimes they must borrow his friend's regiment which is same regiment type. They do that because they didn't have a time to take it at the hospital. But, PLHIV did not drink their ARV regiment when they fell is better and they only multiply exercise to increase their healthy condition.

(Counselor: IB, 45 years)

The behavior of mutual need is always present among PLHIV, for example remind and support each other in medication drinking, especially new PLHA who start ARV therapy. They desperately need information about the benefits, ARV side effects, and how to improve their quality of life.

(Peer support: DL, 43 years)

The interviews results shown that all participants have experience not adherence. Not adherence ARV therapy increases the risk of treatment failure related viral resistance.

CONCLUSION

a. Knowledge of PLHIV

Based on in-depth interviews were conducted among 6 participants shown that most of participants have known basic information about HIV/AIDS. While HIV knowledge will support healthy behaviors because knowledge is a mediator of behavioral change for the individual.⁹

Participants know the transmission mode of HIV/AIDS through needles, sex unsafety, non-sterile blood transfusion, mother to child by blood, semen, and breast milk product. But if mother initiated ARV therapy during pregnancy then risk of mother-to-child HIV transmission by 1%.¹³ In our study, HIV prevention are knowledge enhancement and avoid risk behavior. Previous study reported that health education and condom are recommended in the HIV prevention.^{14,15,16,17} Additional, study in Africa shown that circumcision accepted as an

important strategy for the HIV prevention.^{18,19}

Health education is a long-term behavioral investment. Increasing knowledge of PLHIV can be provided through continuous health education. Its mean, impact of health education can only be seen a few years later. In the short term, health education only produces changes or increases for people's knowledge.²⁰ Previous study shown that Adequate knowledge about HIV and ARV therapy will increase adherence and the quality of life.²¹

b. ARV Access

Health care system should be obtainable in every time needed by society that is distributed based on socioeconomic, community and geographical needs. This study shown that most of participants try not to be known by the crowd when they access ARV therapy. Participants who prefer to access treatment outside of district, they hope the hospital can give a sense of safety, comfort and confidential.

Health worker said that number of PLHIV at Bulukumba district is increased but only 6.9% of PLHIV who started ARV at hospital. PLHIV participant confirmed that they started ARV therapy outside of district because sometimes drugs stock at Bulukumba hospital runs out. Predisposing factor for increasing health care access is health care system.²² PLHIV who is easily to access ARV therapy have twice opportunities to adhere ARV therapy than those who is difficulty to access it.²³

Additional, PLHIV said that health status are closely related seeking health care service. This study support previous studies which access to health care system is strongly influenced by their condition as unhealthy feelings. It is one of indicator to decide accessing health care services.²⁴⁻²⁷ It is therefore a clear understanding of ARV therapy is needed to increase ARV access.²⁷

District health offices (DHO) reported that only 4.3% of PLHIV access ARV therapy at Ujung Bulu sub-district which is Bulukumba hospital established. It shown that goals of fast Track the SDG 2030 program to achieve 90% of people know his HIV status, 90% of people who know his status soon start ARV therapy and 90% who had started ARV therapy showed viral load suppression is still distant.²⁸ This target can achieve with a strategy.

One strategy developed at Uganda is establish Community ARV Group (CAG). It focus on community-based ARV services which facilitate access to ARV therapy, improve ARV therapy adherence by reduce travel time of patients to the clinic or hospital for drugs taking.²⁹

c. Adherence

The successful of ARV therapy is determined by at least 95% of adherence and viral suppression.²⁷ In our study, all PLHIV participants were identified have experience not adherence. Not adhere were caused by negligence of putting drugs on the medicine box, did not on time take drugs, be embarrassment to the health services, distance factors, hoping drugs from peer support, drug side effects, inappropriate drug dosage, stigma, and cost factors. This result is apprehensive because not adherence was identified increasing the risk of treatment failure and viral resistance.³⁰

Others obstacles of adherence were identified among participants such as cost of transportation, accommodation, administration, and blood checks. Previous study identified that the cost burden caused by HIV disease is greater when having ARV therapy. This suggests that although ARV drugs have been provided free of charge by the government but the financial burden of care remains great. Financial problems indirectly can lead to low adherence of PLWHA in taking ARVs.³¹

The side effects and size of ARV regimen are also a detention for adherence. Side effects such as nausea, dizziness, and anemia are most frequently appear in the early treatment. But not all PLHIV who initiated ARV therapy experienced side effect of treatment.²⁶ Stigma is also a factor inhibiting treatment, they feel uncomfortable to pick up their drugs at hospital because stigma. Previous study reported that 50% of PLHIV have to skip the time of drinking medicine because they are fear his friends or family knows their HIV status.³²

The knowledge about ARV therapy, self-motivation, and support from family friends, peer support, health workers, society, and government also are an important for PLHIV adherence.³³⁻³⁸ All parties obliged to keep the rights of PLWHA in obtaining good and optimal health services, particularly ARV services and maintaining therapy.²⁷

Conclusions

Most of PLWHA already know the definition, transmission, prevention and ARV therapy although all participants ever experienced not adherence. PLHIV who started ARV therapy outside Bulukumba district hope they can more secure, comfortable and confidentiality. Gathering place is recommended for PLWHA which is a place of HIV knowledge sharing, mutual support, and ARV therapy reminder to improve their quality of life.

Conflict of Interest : There is no conflict of interest

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