Qualitative Study of Factors Influencing Adherence of People With HIV/AIDS in ARV Consumption in Cilacap Regency

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ABSTRACT

The quality of life of HIV/AIDS people depends on the consumption of antiretroviral drugs. The viral load control response of 85% requires a commitment of 90-95% drug use. If the patient takes ARV 60 times a month, the patient does not miss more than 3 doses. The study aimed to look for factors influencing the compliance of People living with HIV/AIDS with ARV consumption. The research was conducted through qualitative research through in-depth interviews as a data collection technique for five PLHIV and their families, and interviews with peer group support, the Management of the Cilacap Regency AIDS Mitigation Commission, and the Head of VCT Cilacap Hospital carried out triangulation. Data processing techniques were carried out using thematic analysis. Based on the analysis results, 4 themes were obtained: factors that affect the compliance of PLHIV in ARV consumption as follows: internal factors: 1) Reluctance to drink because of boredom; 2) Irregularity of drinking due to forgetfulness; 3) Unwillingness to take ARV because they feel no complaints and external factors: 4) There is still a stigma against PLHIV in the community.

Keywords: Antiretrovirals, HIV/AIDS, compliance, factors

INTRODUCTION

CD4 T cells are produced in the human body every day. This process is vital to help maintain immunity and prevent viruses and bacteria from infecting the body. Human Immunodeficiency Virus (HIV) is a virus that causes Acquired Immuno-deficiency Syndrome (AIDS) by damaging the immune system in the human body. When HIV has entered the human body, the virus can replicate massively, so it is more potent in destroying CD4 cells(Wahyu Suprihatin, 2019). The quality of life of People living with HIV (PLHIV) depends on the consumption of ARV drugs. The viral load control response of 85% requires a commitment of 90-95% drug use. If the patient takes Anti RetroVirus (ARV) 60 times a month, the patient is expected to receive at most three doses. Until now, there is no reminder system for PLHIV about ARV consumption. Several factors affect the compliance of PLHIV in taking ARV, including forgetfulness, fatigue and hopelessness, no symptoms of the disease, and no support from a partner (Chirambo et al., 2019).
ARV therapy aims to treat and prevent complications in HIV patients with Cluster Deference (CD) counts below 500. Consumption of ARV must be according to the dose and time continuously erased because non-adherence to ARV or stopping ARV therapy can cause the body of PLHIV to experience resistance to ARV it can increase the risk of HIV / AIDS infection, as well as high mortality of PLHIV. Based on a study conducted by Hidayati et al. (2018), it was found that the compliance rate of high ARV consumption was 44%, while as many as 34.7% were included in the moderate level category and as many as 21.3% in the low category (Hidayati et al., 2018).

Studies of ARV compliance in India found several things that affect the compliance of PLHIV in ARV consumption, namely financial, family support, social stigma, and side effects felt (Negesa, 2017). Studies of ARV compliance in Jakarta, Indonesia, show a relationship between gender, knowledge of treatment, family support, and health insurance (Debby et al., 2019). The number of HIV/AIDS findings in Cilacap Regency in 2022 was recorded at 2,038 cases. Among the thousands of cases, 25 students had HIV AIDS. Based on information from the P2P section of Cilacap Regency, the level of access to ARV for PLHIV is 100%. However, the level of compliance of PLHIV in Cilacap Regency in consuming ARV is still lacking, which is 31%. This barrier is likely to be a factor in the continued increase in the number of HIV infections in Cilacap Regency. Until 2022, HIV/AIDS cases in Cilacap Regency have reached 2,038. This number makes Cilacap rank 2 in Central Java.

Meanwhile, Central Java was ranked first in Indonesia for increased in cases. This finding requires optimal follow-up to realize Three Zero by 2030: no new HIV-diagnosed patients, no mortality due to HIV/AIDS, and no discrimination found in ODHIV / PLHIV. This study aims to determine the factors that affect the compliance of PLHIV in consuming ARVs.

MATERIAL AND METHODS

The research was conducted through qualitative research with a phenomenological approach to obtain in-depth information about the factors that influence the compliance of PLHIV in ARV consumption in Cilacap Regency. His qualitative method is selected to explore the factors influencing PLHIV adherence in ARVs properly. Data collection was carried out through in-depth interviews. Participants in this study were PLHIV, who had been detected for at least 12 months, as many as 5 people and PLHIV families of as many as 2 people. Triangulation was carried out to 1 member of the Peer Support Group, 2 in charge of VCT Cilacap Hospital, and 2 members of the Cilacap Regency AIDS Commission. The target population in this study is all PLHIV in the Cilacap area, while the affordable population in this study is PLHIV who have been detected HIV positive in the range of one year to 10 years. The criteria for inclusion in sample selection are: have been detected HIV for at least 12 months, willing to be informants and are cooperative. Research sample selection was conducted with KDS to find PLHIV with the required inclusion criteria. Data analysis in this study was carried out after in-depth interviews with informants, followed by making transcripts of in-depth interview results through playback of recordings and sorting data in line with the research theme.

All participants signed an informed consent form at the beginning of the first meeting before fully participating in the research process. An in-depth interview is carried out on a predetermined day, and participants are given awards for their willingness to research activities. The researcher initially explained the purpose of the research to be carried out. The researcher explained that the conversation was recorded. The recording results are scripted, then the coding is done, the same coding is grouped into categories, and the same categories are grouped into themes. This research
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has been declared to have passed ethics through letter Number:1465/KEPK/STIKES-NHM/EC/V11/2022

The instrument in this study is the researcher himself. The researcher himself prepared the questions used in the in-depth interview. Questions are built on theories about factors that affect the compliance of PLHIV in taking ARVs.

The research data were analyzed with thematic analysis. The data obtained through in-depth interviews were transcribed verbatim and directly made verbatim. Credibility is done by member checking, where participants review transcription results to ensure that transcriptions match what was conveyed at the interview. Several things were done to increase the degree of confidence in this research. Credibility is done by member checking, where participants review transcription results to ensure that transcriptions match what was conveyed at the interview. Transferability testing is done by making research reports systematically, in detail, clearly, and reliably. Dependency and confirmability are carried out through peer review by the research team, from the research process to data analysis.

RESULTS AND DISCUSSION
RESULT
The characteristics of the Respondents in this study can be seen in Table 1.

Table 1. People Live With HIV/AIDS Characteristics

<table>
<thead>
<tr>
<th>No</th>
<th>Age (Years)</th>
<th>Gender</th>
<th>Duration of Diagnosis (Years)</th>
<th>Occupation</th>
<th>Level Of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>33</td>
<td>Woman</td>
<td>1</td>
<td>Mother Household</td>
<td>Junior High School</td>
</tr>
<tr>
<td>2</td>
<td>41</td>
<td>Man</td>
<td>3</td>
<td>Private employees</td>
<td>Senior High School</td>
</tr>
<tr>
<td>3</td>
<td>38</td>
<td>Man</td>
<td>2</td>
<td>Private employees</td>
<td>Senior High School</td>
</tr>
<tr>
<td>4</td>
<td>28</td>
<td>Woman</td>
<td>2.5</td>
<td>Mother Household</td>
<td>Junior High School</td>
</tr>
<tr>
<td>5</td>
<td>28</td>
<td>Man</td>
<td>2</td>
<td>Laborer</td>
<td>Senior High School</td>
</tr>
</tbody>
</table>

Source: Primary Data

Based on the results of the theme analysis, it was found that 4 theme factors affect the compliance of PLHIV in consuming ARV in Cilacap Regency. This result can be seen in Table 2 below.

Table 2. Theme Analysis of Factors Influencing PLHIV Compliance in ARV Consumption in Cilacap Regency

<table>
<thead>
<tr>
<th>Code</th>
<th>Category</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>be bored</td>
<td>Bored</td>
<td>Internal factors Non-compliance with ARV consumption: Bored and forgot</td>
</tr>
<tr>
<td>be saturated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>feeling nauseous and unwell</td>
<td>Forget</td>
<td></td>
</tr>
<tr>
<td>Not remember</td>
<td></td>
<td></td>
</tr>
<tr>
<td>forget</td>
<td></td>
<td></td>
</tr>
<tr>
<td>neglect</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because there are no complaints</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
If there are no complaints, there is no need to take medicine
Feeling no complaints
Internal factors Disobedience in taking ARVs because they feel they have no complaints
Do not drink if there are no complaints
Do not feel sick, so do not drink
For fear of being ostracized
Stigma
Refusal to take ARV due to stigma against PLHIV
Fear of being shunned by neighbours
Other people's views on taking medicine

Source: Primary Data

a. Reluctance to take ARVs due to boredom

Based on the results of the study, it was found that respondents did not regularly consume because they felt bored. The statement from the respondents below supports this result:

".........” Even though Mom, it feels boring if I drink every day ... (P1, 33 years)

In addition, respondents said that they were saturated when consuming ARVs every day.

"... “Often I am bored, Mom; I have been taking ARV for 2 years, it's normal for me to feel bored .... “(P3, 38 years)

Reasonable consumption of ARVs must be done with the same dose and time, often making Highly Active Antiretroviral Therapy (HAART), meaning that all ARV drugs are constantly consumed with the correct dose without considering the appropriateness of the right time and method(Harahap et al., n.d.). his makes respondents feel nauseous, as expressed by the following respondents

"......” nausea in the sense that it's eneg, ma'am, kaya is really bored every day you have to take ARV”. (P2, 41years).

Perceptions of the drug influence factors affect PLHIV in ARV consumption. Boredom often makes PLHIV reluctant to consume ARV. Patients required to take the drug every time with the correct dose often experience boredom. Setiyadi (2019) stated that boredom is the dominant factor in the non-compliance of patients with tuberculosis to take drugs(Noor Alis Setiyadi, n.d.). According to the Indonesian Ministry of Health (2014), antiretroviral therapy for people with HIV AIDS reduces mortality and morbidity and increases life expectancy and quality of life of PLHIV. ARV treatment will reduce the frequency of HIV in the body of PLHIV to avoid entering the stage of AIDS. Besides, antiretroviral treatment can prevent comorbid infections and other complications (Rantetampang et al., n.d.). Saturation usually appears when PLHIV has taken antiretrovirals in the range of 6 months. In addition, PLHIV who consume ARV dailywithout pause will feel bored because they do not experience complaints. In addition, the lack of adherence to PLHIV / PLHIV who have received therapy for more than 7 months, also due to other factors such as the burden of treatment costs, consequences or side effects of treatment, and negative views from the surrounding environment that will make PLHIV feel uncomfortable (Haryatiningsih et al., n.d.)

The compliance of PLHIV in consuming ARV is also influenced by other factors, namely the motivation to survive, high awareness of the uses and benefits of antiretrovirals and the level of trust in their religion/belief. The desire of people with HIV to recover and live longer is the most
dominant contributing factor to adherence (Yuniar et al., n.d.). Some people living with HIV have a way of jerking when consuming ARVs by assuming ARVs are vitamins so they do not become a burden. In addition, the answer given when asking questions about drugs taken every day is vitamins and body fattening. This behavior increases adherence to ARV consumption in people with HIV (Curioso et al., 2010).

b. **Reluctance to take ARVs because they forget**

Factors influencing compliance with PLHIV for ARV consumption include disharmony in relationships with health workers, forgetting due to busy schedules, and fear of disclosing HIV status to others, especially men/girlfriends, essential contributors to suboptimal compliance. Social and emotional support and counseling from peer groups are consistently reported as strong adherence drivers (Xu et al., 2017). This situation is following what was expressed by the participants as follows:

.... “I often forget because I sometimes go out of town, like the medicine is not brought...” (P2, 41 years)

Other participants also expressed the forgetting factor in the following expression: “...Actually, what makes me not take medicine, yes, if I forget mom, yes Her name is Woman, Mom, sometimes she thinks a lot’’... (P1, 33 years)

Challenges arise in taking medication daily for chronic conditions and stigma, such as HIV infection, is unavoidable. The challenge that often occurs is the forgetting factor. Consistent adherence to ARVs is essential to suppress HIV successfully. Ideally, PLHIV reaches 80%-95% of the ARV dose on schedule for HIV suppression (Freeman et al., 2021). The factor of forgetting to take ARV is also caused by forgetting to take ARV at VCT. This situation is following what was expressed by the participants as follows:

..... “I sometimes finish the medicine, forget not to take it at the hospital, so I don't drink that day”. (P4, 28 years)

Taking ARVs in hospitals, with varying distances between hospitals and homes of PLHIV, has contributed to the non-compliance of PLHIV in consuming ARVs. Efforts that can be made to improve the compliance of PLHIV in ARV include including the closest people to PLHIV, which do not cover the status of PLHIV from the family. This act can help PLHIV get antiretrovirals in the hospital if PLHIV cannot come to the hospital themselves. Roughly two-thirds of people who missed ≥1 dose of ARVs reported forgetting to take them. Interventions that include reminders can help prevent this deviation. An analysis of a systematic review of ARV compliance interventions found that text messaging interventions were the most successful in improving compliance (Crim et al., n.d.) Increased compliance by health workers should be implemented as an essential program for patients and couples by being professionally trained. This effort is to ensure that their patients understand the benefits of ARV compliance with an understanding of common side effects, long-term positive effects from daily use and persistently, and its relationship with improved quality of life and prevention of HIV transmission (Lahai et al., 2022)

c. **Feeling no complaints**

People with HIV experience an increase in early exposure to the disease caused by a lack of adherence to ARV consumption. Patients who feel no complaints tend to be non-compliant in taking
ARVs. WHO recommends that ARVs be consumed by all patients with HIV, either with complaints or no complaints. Fear of side effects also affects adherence to taking ARVs (Shubber et al., 2016). Participants who felt they had no complaints often made them reluctant to take ARVs. In addition, concerns about the side effects of drug consumption that are carried out continuously also affect the compliance of PLHIV in consuming Antiretroiral. This result follows research conducted in Thailand that concerns of PLHIV about side effects found in 4% of PLHIV who do not comply with taking ARV(Li et al., 2010). As the participant's statement below:

"..." So, sometimes I feel that there are no complaints, so instead of there are side effects that I will receive when taking drugs every day, yes, I don't consume, I consume yes if for example the body is not feeling well, or sick... “(P2, 41 years)

In a study (Golrokhy et al., 2017) 94% of patients exposed to ARVs showed symptoms of adverse effects. The discomfort created by various side effects becomes an important factor that reduces adherence or leads to treatment discontinuation (Iacob et al., 2017). Other parties also conveyed the same thing:

... "Yes, I do sometimes feel that there are no complaints, afraid that my kidneys will have an effect because I take medicine every day, so I want to rest first, later if there are new complaints I drink again.” (P5, 28 years)

Overcoming side effects experienced due to consuming ARV can be done by consuming post-ARV complaint-reduction foods. The absence of reducing food can also hinder OSHA from taking ARVs. This result is consistent with the review that food insecurity results in non-compliance through two mechanisms: stopping ARVs when food is unavailable avoiding exacerbated (gastrointestinal) side effects, or being unable to take ARVs while working to meet basic needs(Heestermans et al., n.d.)

d. External factors: stigma against PLHIV by their environment

Currently, the stigma against PLHIV is still relatively large, stigma is a treatment to describe PLHIV because of its HIV status. PLHIV often wants to keep their HIV status closed from the surrounding environment. This act is one of the obstacles to adherence to ARV consumption. One of the reasons is to feel meaningless when he has taken ARVs, but people still discriminate against them. This result is in accordance with the napa conveyed by the participants:

"..." Currently, stigma against PLHIV is still relatively large, Stigma is a treatment to describe PLHIV because of its HIV status. PLHIV often wants to keep their HIV status closed from the surrounding environment, this is one of the obstacles in adherence to ARV consumption. One of the reasons is to feel meaningless when he has taken ARVs, but people still discriminate against them. This is in accordance with the napa conveyed by the participants...."(P3)

In line with that, it was also revealed that:

"..." Even if I take ARV every day, it's not late, but anyway people still don't want to accept me, I lost my job, so I feel there is no point in taking ARV..."(P4)

The statement of the PLHIV family reinforces this: .... Yes, it is not blamed, indeed we are the only ones whose families are also often afraid if they take medicine, yes, there are cynical views towards patients and even to us ... (PLHIV/AIDS’s family)
The existence of stigma makes PLHIV keep their HIV status secret to prevent discrimination in themselves, and behavior to hide one's HIV status interferes with optimal adherence to ARV consumption (Mitzel et al., 2019). This result is in line with the results of Habibi and Supodo's research (2020) on people living with HIV/AIDS in Kendari, with a total of 48 respondents showing that there were 17 respondents (35.5%) with people living with HIV/AIDS with the stigma of non-adherence to ARV treatment and 31 respondents (35.5%) with HIV/AIDS in Kendari. respondents (64.5%) who took ARV treatment (Habibi et al., n.d.). Efforts to reduce the stigma of PLHIV continue. Following the program launched by the government with "three zero: no new patients, no deaths from HIV/AIDS, and no stigma on PLHIV. Several factors, including the form and impact of drug consumption, negative perceptions or stigma from the community, and no complaints, influence PLHIV compliance in ARV consumption (Mukarromah & Azinar, 2021). Some PLHIV argue that the stigma in the community is due to a lack of knowledge about HIV, so people are worried about being infected. This concern resulted in the community ostracizing PLHIV. Discrimination and stigma experienced by PLHIV contribute to non-compliance of PLHIV in consuming ARV. (Sekoni et al., 2012).

CONCLUSION AND SUGGESTION

Based on the results of the study, it was found that several factors affect the compliance of PLHIV in ARV consumption in Cilacap Regency: internal factors: feeling bored, forgetting, feeling no complaints and external factors of stigma by the environment to PLHIV. Based on the results of this study, it is necessary to create a reminder system that is easy to use by PLHIV and their families to increase the level of compliance of PLHIV in taking antiretrovirals, with the preparation of menus and features through the involvement of KDS as part of striving to increase PLHIV compliance in ARV consumption. In addition, it is also necessary to create a guidebook for PLHIV care at home that PLHIV families can use as a reference in carrying out PLHIV treatment.

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CONFLICT OF INTEREST

Researchers stated that there was no conflict of interest with funders, organizations and respondents in the study.

REFERENCES


