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Factors Influencing Loss to Follow-Up in HIV Patients: a Retrospective Study

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ABSTRACT

Background: HIV has become a global health problem, causing millions of deaths since its discovery. The success of antiretroviral therapy (ART) depends heavily on patient adherence, yet the lost-to-follow-up (LTFU) rate remains high. **Purpose:** This study aims to identify the characteristics of HIV patients experiencing LTFU and analyze the influencing factors at the Karang Panjang Community Health Center in Ambon City. **Methods:** This study employs a cross-sectional design with secondary data analysis from the medical records of HIV patients from 2018 to 2024. The sampling technique used was total sampling, with a total sample size of 152 patients. Data analysis was conducted descriptively and inferentially using the chi-square and Fisher's exact test. **Result:** The prevalence of LTFU among HIV/AIDS patients at the Karang Panjang Community Health Center is 15.1%. Most LTFU patients are female, over 30 years old, and married. Statistical tests show significant associations between LTFU and age ($p = 0.0468$), sex ($p = 0.0433$), and marital status ($p = 0.0355$), while education and religion are not significant. Among LTFU cases, 8.3% had died, 50% were alive but had stopped therapy, and 41.7% were untraceable. Additional contributing factors identified through discussions and medical record reviews include inadequate counseling and education, poor documentation of ARV side effects, limited financial resources, and insufficient peer or family support. **Conclusion:** The study concludes that age, sex, and marital status contribute to LTFU among HIV patients. It recommends improving ART retention through education, stricter monitoring, and community-based strategies to reduce future LTFU rates.

Keywords*:* HIV/AIDS, lost to follow-up, antiretroviral therapy, patient adherence, risk factors.

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BACKGROUND

Human immunodeficiency virus (HIV) was first identified in 1983 and had claimed approximately 40.4 million lives worldwide by 2022. This figure is alarming, and if left unaddressed, HIV could become a global health crisis. Various efforts have been made to improve access to and adherence to antiretroviral therapy (ART), which has been proven to suppress viral load, extend life expectancy, and reduce the risk of transmission. However, the success of ART heavily depends on the patient's consistent adherence to long-term treatment. Most patients diagnosed with HIV will progress to acquired immune deficiency syndrome (AIDS) within ten years if left untreated. With the initiation of ART after an AIDS diagnosis, patients can live more than ten years and even achieve a normal life expectancy. However, once diagnosed with AIDS and not receiving ART, patients may die within two years.[1,2,3]

Globally, in 2023, approximately 39.9 million people were living with HIV, with an estimated range of 36.1 million to 44.6 million. Among them, around 38.6 million were adults aged 15 and older, while approximately 1.4 million were children aged 0 to 14. Additionally, 53% of the total population living with HIV were women and girls. In 2023, 86% of all people living with HIV had learned their HIV status, but around 5.4 million people were still unaware of their infection. Among those who knew their status, 89% accessed treatment, and among those who received treatment, 93% achieved viral suppression. Overall, in 2023, 86% of all people living with HIV knew their

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status, 77% were on treatment, and 72% successfully achieved viral suppression.[4,5]

Based on the 2024 Rapid Risk Assessment Report on monkeypox (MPOX), the estimated number of people living with HIV (PLHIV) in Indonesia in 2024 is 503,261. Among them, 351,378 individuals are aware of their HIV status, while 217,482 (62%) are receiving antiretroviral (ARV) treatment. Additionally, 99,463 individuals (46%) have undergone viral load testing, and 91,662 (42%) have achieved viral suppression. Ambon City has the highest prevalence of HIV/AIDS cases in the Maluku province. Each year, the number of cases in this region continues to increase. The number of HIV cases in Ambon City rose from 171 in 2022 to 376 in 2023. Meanwhile, in the working area of Karang Panjang Public Health Center, there were a total of 126 cases recorded from 2018 to 2023, with 25 cases reported in 2023.[6,7,8]

HIV/AIDS rises, non-adherence to ARV therapy can have severe negative effects. Studies have shown that missing just one or two doses of ARV medication per week can significantly impact HIV/AIDS treatment outcomes.[8,9,11]

In Indonesia, the LTFU rate among HIV patients remains a significant challenge. The number of people living with HIV (PLHIV) starting ART has been increasing from 2021 to 2024. However, based on cohort data from each year, some PLHIV discontinue treatment and are considered LTFU. The LTFU data for PLHIV in the working area of Karang Panjang Public Health Center from 2018 to 2024 shows that 21 PLHIV have been lost to follow-up. Many patients diagnosed with HIV do not return for treatment after a few visits. Several factors contribute to the occurrence of LTFU among HIV patients undergoing ART, including demographic, clinical, and socio-environmental aspects.

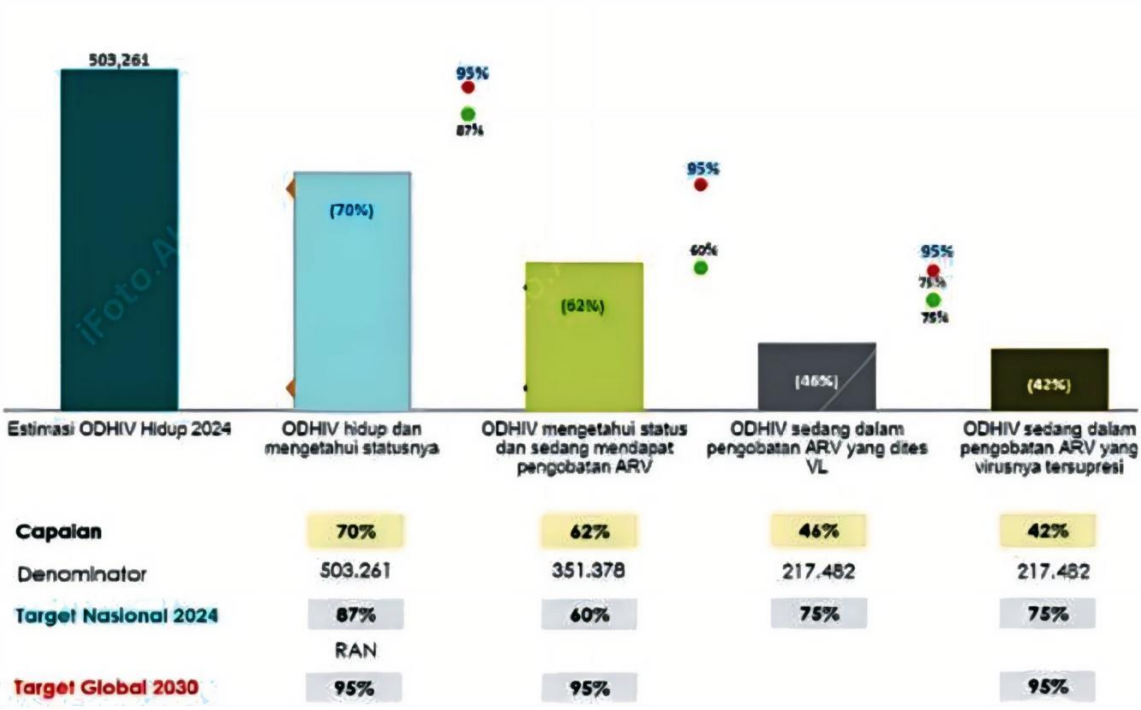

Figure 1. Data of People Living with HIV (PLHIV) in Indonesia in 2024.

One of the most significant challenges in HIV management is the high rate of lost to follow-up (LTFU), referring to patients who no longer continue regular medical care. Lost to follow-up occurs when HIV patients who have previously started antiretroviral (ARV) treatment fail to visit healthcare facilities for a certain period, typically more than 90 days, without prior notice or a clear reason. The high LTFU rate among HIV patients has serious consequences for both individuals and society. As the prevalence of

Demographic factors such as age and sex have been shown to influence LTFU rates, where younger patients, particularly adolescents and young adults, tend to have lower adherence due to psychological immaturity, denial, and challenges related to lifestyle and stigma. Men are also more likely to be lost to follow-up due to higher mobility, employment outside the region, and lower health-seeking behavior compared to women. Education level and socioeconomic status also play a crucial role; patients

with lower education may have a limited understanding of the importance of lifelong ART adherence and are less likely to access or effectively interpret health information. Individuals with lower socioeconomic status may face financial barriers to transportation and healthcare access, which can impede their ability to attend routine follow-up visits.[8,10]

Clinical factors also significantly contribute to LTFU, including patient's perceptions of their health status. For instance, patients with a higher CD4 count or those who feel physically well may prematurely assume they no longer need ART, leading to disengagement from care. Inadequate documentation and management of drug side effects can also discourage patients from continuing treatment.[9] Furthermore, limited access to healthcare services, such as long travel distances to clinics, long waiting times, and understaffed health facilities, serves as an additional barrier. The presence of social stigma remains a prominent deterrent, with many patients fearing discrimination if their HIV status is disclosed, which discourages them from seeking treatment consistently.[6] Moreover, lack of family or peer support can exacerbate feelings of isolation, especially among unmarried patients or those without a reliable support system, ultimately increasing their risk of being lost to follow-up. These interconnected factors highlight the need for a comprehensive, multi-faceted approach to improve patient retention and adherence to ART.[6,7,9]

Based on reports of LTFU among HIV/AIDS patients and the limited attention paid to this issue, as well as the lack of data and research conducted at Karang Panjang Public Health Center, the researcher is interested in studying the factors influencing lost follow-up among HIV/AIDS patients receiving ART at this health center. Greater knowledge of the elements that contribute to LTFU is likely to increase patient retention in HIV therapy, boosting efforts to combat the HIV/AIDS epidemic. As a result, this study aims to identify the distinctive characteristics of HIV patients classified as LTFU and analyze the factors that enhance LTFU among HIV patients.

METHODS

This study employs an analytical observational design with a cross-sectional approach, aiming to examine the relationship between variables by observing and collecting data at a single point in time, without any intervention. The objective is to analyze the factors contributing to LTFU among HIV patients. The study uses secondary data from the medical records of HIV patients during the period from 2018 to 2024.

The target population of this study includes all HIV patients receiving treatment at Karang Panjang Public Health Center. In contrast, the accessible population and research sample consist of HIV patients who do not regularly seek treatment at the health center. The target population of this study includes all HIV patients receiving treatment at the Karang Panjang Public Health Center. In contrast, the accessible population and research sample consist of HIV patients who do not regularly attend therapy at the health center. The sampling technique used is total sampling, which involves selecting all HIV patients who were not periodically undergoing treatment during the study period. The inclusion criteria for this study are HIV patients recorded in medical records who did not routinely attend visits during the study period, referring to the World Health Organization (WHO) definition of LTFU, which is defined as patients lost from care who have not received clinical, laboratory, or pharmacy services for at least 6 months. The exclusion criteria are patients with incomplete or unavailable medical records during the study period. Data collection was conducted by reviewing the medical records of HIV patients from 2018 to 2024, which were available at the health center. Ethical approval was obtained under the reference number No. 112/FK-KOM.ETIK/VI/2025

Data analysis is conducted descriptively using Microsoft Excel and the Statistical Product and Service Solution (SPSS) software. The results are then presented in tables and narratives to facilitate interpretation. Hypothesis testing is performed using the chi-square test. The requirements for the chi-square test include assessing the relationship between variables in rows and columns, where the data is measured on a nominal or ordinal scale, a maximum of 20% of cells have an expected count of less than 5, and a sample size of more than 20. If the chi-square test assumptions are not met, an alternative Fisher's exact test can be used. Decision-making is based on the significance value (Asymp. Sig). If the Asymp. Sig. (2-sided) value is < 0.05, H0 is rejected, whereas if the Asymp. Sig. (2-sided) value is ≥ 0.05, H0 fails to be rejected.

RESULT

This study was conducted on HIV/AIDS patients undergoing ART at Karang Panjang Public Health Center in Ambon City. The sampling method used was total sampling. The study included 152 HIV/AIDS

patients who received treatment at Karang Panjang Public Health Center from 2018 to 2024.[11]

Both LTFU and non-LTFU patients were predominantly female and aged 20 years or older. Similar results were found regarding marital status, religion, and the highest level of education. The majority of both LTFU and non-LTFU patients were married, adhered to a non-Islamic religion, and had a high level of education, equivalent to senior high school or higher.

Table 1. HIV patients' characteristics based on sex, age, religion, education, and marital status

Variable	n	%
Sex		
Man	69	45.4
Woman	83	54.6
Age (years)		
< 30	57	37.5
≥ 30	95	62.5
Religion		
Islamic	57	37.5
Non Islamic	95	62.5
Educational Status		
<Highschool	57	37.5
≥ Highschool	95	62.5
Marital status		
Married	67	44.1
Not married yet	85	55.9
Total	152	100

After analyzing respondent characteristics in relation to LTFU using the chi-square test, three factors were found to be statistically significant ($p < 0.05$): age, sex, and marital status. Meanwhile, two other factors—education level and religion—were not statistically significant ($p \geq 0.05$). In general, lost to follow-up patients fall into three categories: deceased, still alive, and untraceable. Among the 24 LTFU patients who were traced, it was found that two patients (8.3%) had died but were not reported to Karang Panjang Public Health Center. Out of the total patients, Karang Panjang Public Health Center reported 12 (50.0%) as deceased, while 10 (41.7%) remained untraceable, indicating a loss to follow-up. Among the surviving patients, most had transferred to the nearest healthcare facility according to their residential address without notifying Karang Panjang Public Health Center (5 patients; 41.7%), whereas seven patients (58.3%) had discontinued therapy.

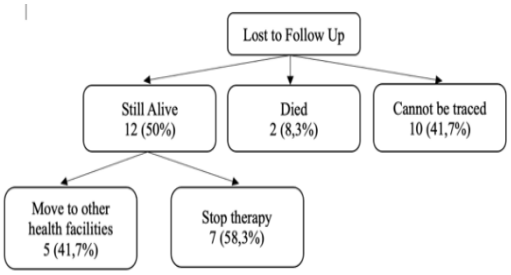

Figure 2. Lost track of the patient's follow-up distribution scheme.

Table 2. Association between respondent characteristics and loss to follow-up

Variable	Lost to Follow-up n (%)	Not Lost to Follow-up n (%)	Significatio n (p)
Sex			
Man	14 (9.2)	69 (46.7)	0.0433
Woman	10 (6.6)	55 (37.5)	
Age (years)			
< 30	5 (3.3)	52 (34.2)	0.0468
≥ 30	19 (12.5)	76 (50.0)	
Marital Status			
Married	11 (7.2)	56 (36.8)	0.0355
Not married yet	13 (8.6)	72 (47.4)	
Religion			
Islamic	12 (7.9)	45 (29.6)	0.107
Non Islamic	12 (7.9)	83 (54.6)	
Educational Status			
<Highschool	11 (7.2)	46 (30.3)	0.589
≥Highschool	13 (8.6)	82 (53.9)	

After analyzing the questionnaire results, three factors were found to be statistically significant ($p < 0.05$): age ($p = 0.0468$), sex ($p = 0.0433$), and marital status ($p = 0.0355$). Meanwhile, two other factors—education level ($p = 0.589$) and religion ($p = 0.107$)—were not statistically significant ($p \geq 0.05$).

DISCUSSION

The average number of HIV/AIDS patients regularly taking ARV treatment each year was found to be 18 patients. Meanwhile, the average number of patients classified as LTFU per year was three patients. As a result, the prevalence of LTFU among HIV/AIDS patients at Karang Panjang Public Health Center in Ambon City was 15.1%. This prevalence rate is lower than the 17.32% prevalence of patients LTFU reported by the Indonesian Ministry of Health. A similar trend was observed in KwaZulu-Natal, South Africa

(24.1%), and in a study by the TREAT Asia HIV Observational Database (TAHOD), which reported a prevalence of 21.4% for patients LTFU in the Asia-Pacific region [12,13]

Among the 24 HIV/AIDS patients classified as LTFU, it was found that two patients (8.3%) had died and were not reported to Karang Panjang Public Health Center in Ambon City. Fourteen patients who are LTFU tend to be non-adherent to treatment guidelines and fail to achieve viral suppression. This condition is associated with potential risks such as higher mortality due to treatment failure, coinfections with opportunistic diseases, and the possible transmission of HIV to uninfected sexual partners.[14]

Among the LTFU patients who were still alive, 7 (58.3%) had discontinued therapy. Previous studies have found that many LTFU patients do not collect their ARV medication due to work commitments and having jobs outside the region, making it difficult for them to visit healthcare facilities. This finding is consistent with a cohort study by Helen Bygrave *et al*., which showed that the rate of LTFU increased among patients working outside the city after more than three months of follow-up. Other studies have also reported that many lost to follow-up patients discontinue their therapy because they feel healthy after their initial visit and believe they no longer need ARV treatment. Patients with a CD4 count above 200 often feel healthy and not highly vulnerable; thus, while positive experiences with healthcare providers remain essential, they may not be considered crucial.[15,16]

The number of living patients at Karang Panjang Public Health Center was 12 (50.0%), compared to 23% of the total patients in Malawi. Among the 12 (50.0%) living patients, most (5 patients, 41.7%) had transferred to a nearby public health center based on their home address without informing Karang Panjang Public Health Center. This phenomenon was mainly because many HIV/AIDS patients receiving treatment at Karang Panjang Public Health Center resided outside the Karang Panjang sub-district, making it difficult to report their status back to the facility. This finding aligns with a study conducted in Nigeria, which identified a long distance to the clinic as one of the primary reasons for patients being LTFU, affecting 56% of them.[16]

Hypothesis testing results indicated a significant association between age and LTFU, with a p-value of 0.0468. Similarly, sex ($p = 0.0433$) and marital status ($p = 0.0355$) also showed significant associations ($p < 0.05$). A study in Ethiopia found that adolescents were twice as likely, and adults were 1.4 times more likely to be LTFU compared to children. A study in Uganda showed that mortality rates were lower among children, suggesting that competing mortality risks may impact this age group. Children are also less exposed to stigma and discrimination (two common risks for loss to follow-up), and caregivers or parents are more likely to ensure that children adhere to treatment, reducing the likelihood of loss to follow-up. Researchers have identified several challenges during adolescence that can impede positive HIV treatment outcomes. Adolescents may be more resistant to treatment, lack caregivers (unlike younger children), exhibit immature analytical thinking, and face specific challenges related to puberty, contributing to higher LTFU rates. Previous studies have also shown that adherence is lower among adolescents compared to adults.[17,18]

Regarding sex as a factor, several studies have indicated that men are more likely to be LTFU due to higher mobility and the risk of substance abuse, which can interfere with adherence. Many men with drug addiction may experience higher toxicity due to interactions with ARV medications, leading to treatment discontinuation. Another influencing factor is marital status, which affects the likelihood of patients being LTFU. This finding is consistent with previous studies showing that family support and perception of disease severity significantly impact the occurrence of LTFU among HIV/AIDS patients. Patients receiving strong family support tend to be more adherent to ART, reducing the risk of loss to follow-up. Marital status can influence LTFU rates among HIV/AIDS patients undergoing ART. Several studies have shown that unmarried patients, including those who are single, divorced, or widowed, tend to have a higher risk of being lost to follow-up compared to married patients. This occurrence is likely due to the lack of social and emotional support typically provided by a spouse, which can affect treatment adherence.[19,20,21]

Patients who reported discontinuing therapy cited reasons such as work commitments or daily activities that prevented them from continuing treatment. A statistically significant association was found between certain variables, including age, sex, and marital status, and the likelihood of loss to follow-up. Efforts are needed to maintain or reduce the prevalence of LTFU among HIV/AIDS patients at Karang Panjang Public Health Center, which is significantly lower than the national LTFU rate. Furthermore, further research should be conducted using a cohort study design and

different data collection methods, such as focus group discussions.

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