

Short Communication

Risk Factors for Loss to Follow-up in HIV Care: A Retrospective Cohort Study in Dili, Timor-Leste

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ABSTRACT

Background: Loss to follow-up (LTFU) among people living with HIV/AIDS (PLWHA) is a public health challenge that reduces the effectiveness of antiretroviral therapy (ART), increases the risk of transmission, and contributes to increased mortality. **Objective:** This study aimed to identify the risk factors for LTFU among patients with HIV in Dili, Timor-Leste. **Methods:** This retrospective cohort study used secondary data from 150 HIV-positive patients at the Community Progress Association (AK-P) in Dili from 2014-2022. The inclusion criterion was adult patients aged ≥ 15 years who started ART with a minimum follow-up of 183 days. Descriptive statistics, chi-square tests, logistic regression, and Kaplan-Meier analysis were used to identify the factors affecting LTFU. **Results:** Of the 150 patients, 72% remained under care, 20.6% experienced LTFU, and 7.3% died. The majority were male (90%), with men who had sex with men (MSM) having a 40% lower risk of LTFU than female sex workers (FSW). Patients aged ≥ 54 years had a 21% lower risk, and married individuals had a 26% lower risk than single individuals did. High income and ART initiation were protective factors, while a CD4 count < 200 cells/mm³ increased the risk of LTFU by 4.2 times, and a viral load > 1000 copies/mL increased the risk by 2.79 times. Level 1 ART was associated with 97% survival at 1, 3, and 5 years, whereas level 2 ART was associated with only 3.6% survival in the first year. **Conclusion:** Sociodemographic and clinical variables influenced LTFU in HIV care in Timor-Leste. Tailored interventions for high-risk groups and improved monitoring and support systems are needed to improve retention and treatment outcomes.

KEYWORDS

HIV; loss to follow-up; antiretroviral therapy; Timor-Leste; patient retention; infectious disease

ARTICLE INFO

Received Jul 31, 2025
Revised Aug 12, 2025
Accepted Sept 15, 2025
Online Sept 30, 2025

EDITOR

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CITE THIS ARTICLE

Amaral BVDC., Yeom JS., Machado FDN., Marques MDS., and Soares NG. (2025). Risk factors for loss to follow-up in HIV care: A retrospective cohort study in Dili, Timor-Leste. *Svāsthya: Trends in General Medicine and Public Health*, 2(5): e141. <https://doi.org/10.70347/svsthy.v2i5.141>.



Supplemental data for this article can be accessed online at <https://doi.org/10.70347/svsthy.v2i5.141>

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INTRODUCTION

HIV/AIDS remains a global health burden, with 38.4 million people living with it by the end of 2021 [1,2]. Despite the availability of antiretroviral therapy (ART), retention in care remains a challenge, particularly in low-income and middle-income countries. Timor-Leste, a lower-middle-income country in Southeast Asia, has experienced an increase in HIV cases since its first detection in 2003, with the majority of infections occurring in the 25–44 years age group, and is associated with uncontrollable behavioral and structural risk factors [3].

Loss to follow-up (LTFU) is a condition in which patients discontinue treatment without documentation of transfer or death and fail to continue treatment, leading to poor health outcomes and increased community transmission [4,5]. LTFU reduces the success of ART programs by decreasing viral suppression, increasing drug resistance, and contributing to morbidity and mortality [6]. Previous research in sub-Saharan Africa revealed LTFU rates ranging from 20–30% in the first year of ART, whereas in Asia, the rates range from 10–40% depending on the care setting [7,8].

LTFU risk factors vary across populations and regions. Previous studies have identified sociodemographic determinants, such as young age, single status, low education, and high mobility, as predictors of LTFU [9]. Clinical factors include advanced HIV stage, low CD⁴ count, unsuppressed viral load, and ART side effects [10,11]. Key populations, such as female sex workers (FSW), men who have sex with men (MSM), and injecting drug users, face a greater risk of LTFU due to stigma, discrimination, and barriers to accessing health services in these areas [12–14].

In Timor-Leste, data on factors contributing to LTFU among PLHIV are limited, making it difficult to implement effective intervention strategies to minimize LTFU cases and events. Most LTFU studies originate from Africa and Southeast Asia, which have different epidemiological contexts and health systems. This knowledge gap hinders the development of evidence-based interventions tailored to local conditions in Timor-Leste. This study sought to fill this gap by investigating the sociodemographic and clinical risk factors associated with LTFU among HIV-positive patients registered with the Community Progress Association (AK-P), the main HIV service provider in Dili. By identifying these risk factors, this study aimed to inform strategies to strengthen patient retention, optimize ART programs, and improve HIV outcomes in Timor-Leste. These findings are expected to have implications for health program planning and better resource allocation in HIV care in resource-limited settings.

MATERIALS AND METHODS

Study design and setting

A retrospective cohort study was conducted at the Community Progress Association (AK-P) HIV Clinic in Dili, Timor-Leste (Figure 1). The AK-P is a nongovernmental organization that provides comprehensive HIV services, including testing, counseling, ART, and psychosocial support. Data were collected from the medical records of HIV-positive patients registered between January 2014 and December 2022, a period that includes the implementation of the treat-all policy in Timor-Leste.

Population and sampling

The study population consisted of HIV-positive patients receiving treatment at AK-P. The total sampling technique included all patients who met the inclusion criteria during the study period. A final sample of 150 patients was determined on the basis of the availability of complete data.

Inclusion and exclusion criteria

The inclusion criteria were as follows: (1) confirmed HIV diagnosis through serological testing, (2) documented initiation of ART, (3) age ≥ 15 years at registration, and (4) a minimum of 183 days of follow-up since ART initiation. The exclusion criteria were as follows: (1) patients who did not start ART, (2) patients with incomplete or missing follow-up data, and (3) patients who were transferred to another facility with complete documentation.

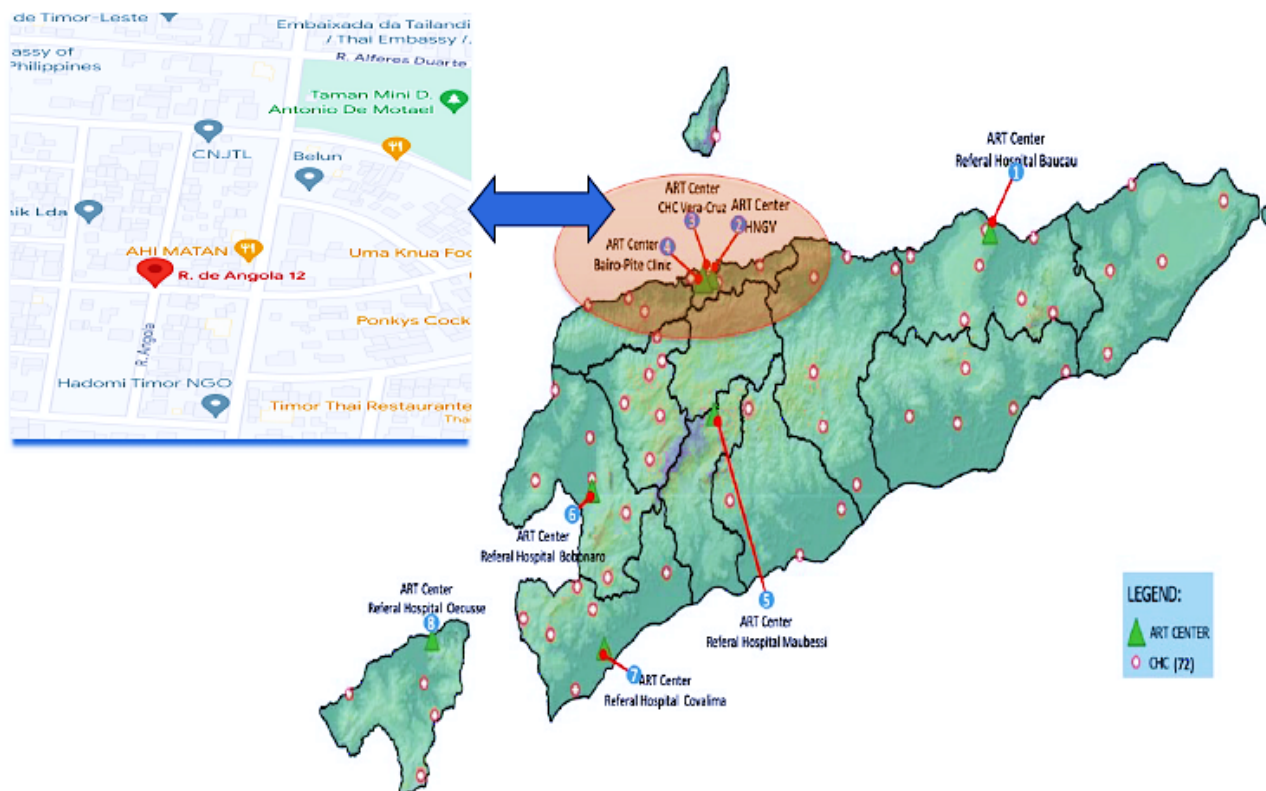


Figure 1. Setting area of the ART Center in Dili Timor-Leste from Google Maps®

Research procedures

Data were extracted from electronic and paper medical records via a standardized data extraction form. LTFU was defined as no clinic visits or ART collection for ≥ 90 days since the last scheduled visit, without documentation of transfer or death, following the WHO definition [4]. Patient status was categorized as follows: (1) retained in care - remained active during follow-up, (2) LTFU met the LTFU definition, and (3) deceased - documented death.

Instruments and variables

Sociodemographic variables included age (years), sex, sexual orientation (MSM, FSW, transgender), marital status (single, married, divorced), education level, and monthly income. The clinical variables included the CD4 count at ART initiation (cells/mm³), viral load (copies/mL), ART regimen (level 1, first-line; level 2, second-line), and reported ART side effects.

Data extraction and analysis

The data were analyzed via Jamovi version 2.3 and R version 4.2. Descriptive statistics (frequency, percentage, mean, and standard deviation) were used to assess patient characteristics. The chi-square test was used to evaluate bivariate associations between categorical variables and LTFU status. Multinomial logistic regression was used to identify independent predictors of LTFU by calculating odds ratios (ORs) and 95% confidence intervals (CIs). Kaplan-Meier survival analysis was used to estimate the probability of retention in care over time stratified by the ART regimen. The significance level was set at $P < 0.05$.

Ethical considerations

This study was approved by the Ethics Committee of the National Institute of Public Health, Timor-Leste (reference number: 60 GPCD-INSPTL/V/2023). Permission to access and analyze patient data was obtained from the Community Progress Association (AK-P) in Dili. All the data were anonymized to ensure confidentiality.

RESULTS

Demographic and clinical characteristics

Among the 150 patients analyzed, 72% (n=108) remained in care, 20.6% (n=31) experienced LTFU, and 7.3% (n=11) died during the follow-up period. The majority of patients were male (90%, n=135), with a median age at ART initiation of 25–39 years (46.7%, n=70). The youngest age group, 17–24 years, comprised 47.3% (n=71), whereas those aged >54 years comprised only 2% (n=3). The distribution of sexual orientation was 52.7% (n=79), 38% (n=57), and 9.3% (n=14) among MSM. The marital status was predominantly single (81.3%, n=122), followed by married (16%, n=24) and divorced (2.7%, n=4). The majority of participants had a junior high school education (88%, n=132), and 11.3% (n=17) had a senior high school education. A monthly income <115 USD was reported by 88% (n=132) of the patients, reflecting the low socioeconomic status of the study population (Table 1).

Table 1. Demographic and clinical characteristics of the participants

Characteristics	N (%)
Gender	
Male	135
Female	15 (10)
Age (years)	
17–24 years	71 (47.3)
25–39 years	70 (46.7)
40–54 years	6 (4)
>54 years	3 (2)
Sexual orientation	
MSM	14 (9.3)
FSW	79 (52.7)
Transgender	57 (38)
Marital status	
Single	122 (81.3)
Married	24 (16)
Divorced	4 (2.7)
Education	
Elementary school	0
Junior High school	132 (88)
Senior High School	18 (12)
Diploma/College	0 (0)
Income (USD)	
<115 USD	132 (88)
≥115 USD	18 (12)

Survival analysis on the basis of ART status

Kaplan-Meier survival analysis revealed a marked difference in survival between the level 1 and level 2 ART regimens. Patients on Level 1 ART (first-line regimen) had a consistent survival rate of 97% (95% CI: 93.7–100%) at 12, 36, and 60 months of follow-up. At 12 months, 93 of the 96 patients remained in care with only three events of LTFU or death. This high survival rate persisted for 60 months, with 15 patients still at risk at the end of the observation period. In contrast, patients on level 2 ART (second-line regimen) had a low survival rate of only 3.6% (95% CI: 0.5–24.5%) at 12 months. Among the 31 patients who started Level 2 ART, only four remained at risk after 12 months, with 27 experiencing LTFU or death. This drastic difference in survival rates reflects the greater severity of disease in patients requiring second-line therapy, the possible failure of first-line therapy, and the complexity of clinical management (Table 2).

Table 2. Survival analysis of patients on the basis of antiretroviral therapy level

ART Level	Time (months)	Number at Risk	Event	Survival (%)	95% CI
Level 1	12	93	3	97.0	93.7-100
Level 1	36	35	0	97.0	93.7-100
Level 1	60	15	0	97.0	93.7-100
Level 2	12	4	27	3.6	0.5-24.5

Clinical risk factors associated with LTFU

Multinomial logistic regression identified three clinical factors as predictors of LTFU. The CD⁴ count was strongly negatively correlated with LTFU (coefficient = -0.560; SE = 0.064; t = -8.732; p < 0.001). Patients with a CD⁴ count < 200 cells/mm³ had a 4.2-fold greater risk of LTFU than those with a CD⁴ count ≥ 500 cells/mm³ did, indicating that severe immunosuppression increases the likelihood of dropout from treatment. The viral load was positively correlated with LTFU (coefficient = 1.009, SE = 0.040, t = 25.376, p < 0.001). Patients with a viral load >1000 copies/mL had a 2.79-fold greater risk of LTFU than those with a suppressed viral load (≤1000 copies/mL). An unsuppressed viral load reflects suboptimal adherence or treatment failure and contributes to dropout. The ART side effects showed a negative but statistically nonsignificant correlation (coefficient = -0.046; SE = 0.032; t = -1.473; p = 0.143). Although not significant, this trend suggests that patients with side effects tend to have a greater risk of LTFU, underscoring the importance of side effect management in maintaining adherence (Table 3).

Table 3. Clinical risk factors associated with loss to follow-up

Variable	Coefficient	Standard Error	t value	p value
CD ⁴ Count	-0.560	0.064	-8.732	<0.001***
Viral Load	1.009	0.040	25,376	<0.001***
Side Effects	-0.046	0.032	-1.473	0.143

Remarks: *** indicates statistical significance at the 95% confidence interval

Sociodemographic factors affecting retention

MSM had a 40% lower risk of LTFU than FSW did (OR = 0.60; 95% CI: 0.38–0.95; p = 0.031). This difference is likely related to higher health literacy and better access to health services among MSM. Patients aged ≥54 years had a 21% lower risk of LTFU than younger patients did (OR = 0.79; 95% CI: 0.64–0.98; p = 0.035), reflecting a greater commitment to care among older patients. Marital status was protective, with a 26% lower risk of LTFU than single individuals (OR = 0.74; 95% CI: 0.56–0.97; p = 0.028), indicating the role of partner support in maintaining adherence. Higher income reduced the risk of LTFU by 35% (OR = 0.65; 95% CI: 0.48–0.88; p = 0.005), reflecting economic barriers to accessing health services. ART initiation reduced the risk of LTFU by 45% (OR = 0.55; 95% CI: 0.42–0.72; p < 0.001), emphasizing the importance of early access to therapy (Figure 2).

DISCUSSIONS

This study identified sociodemographic and clinical risk factors associated with LTFU in patients with HIV in Dili, Timor-Leste. These findings confirm that young age, single status, low income, and advanced disease (low CD⁴ count and high viral load) increase the risk of LTFU, whereas ART initiation, marital status, older age, and higher income are protective factors. A CD⁴ count <200 cells/mm³ increased the risk of LTFU by 4.2 times, which is consistent with a study in Ethiopia that reported that patients with a CD⁴ count <200 cells/mm³ had a 2.8 times greater risk of LTFU [10]. Severe immunosuppression is correlated with poor physical condition, opportunistic infections, and hospitalization, which hinder regular clinic attendance. In the Democratic Republic of Congo, Buju et al. [11] reported that a CD⁴ count <100 cells/mm³ was an independent predictor of LTFU, with an OR of 3.4 (95% CI: 2.1–5.5).

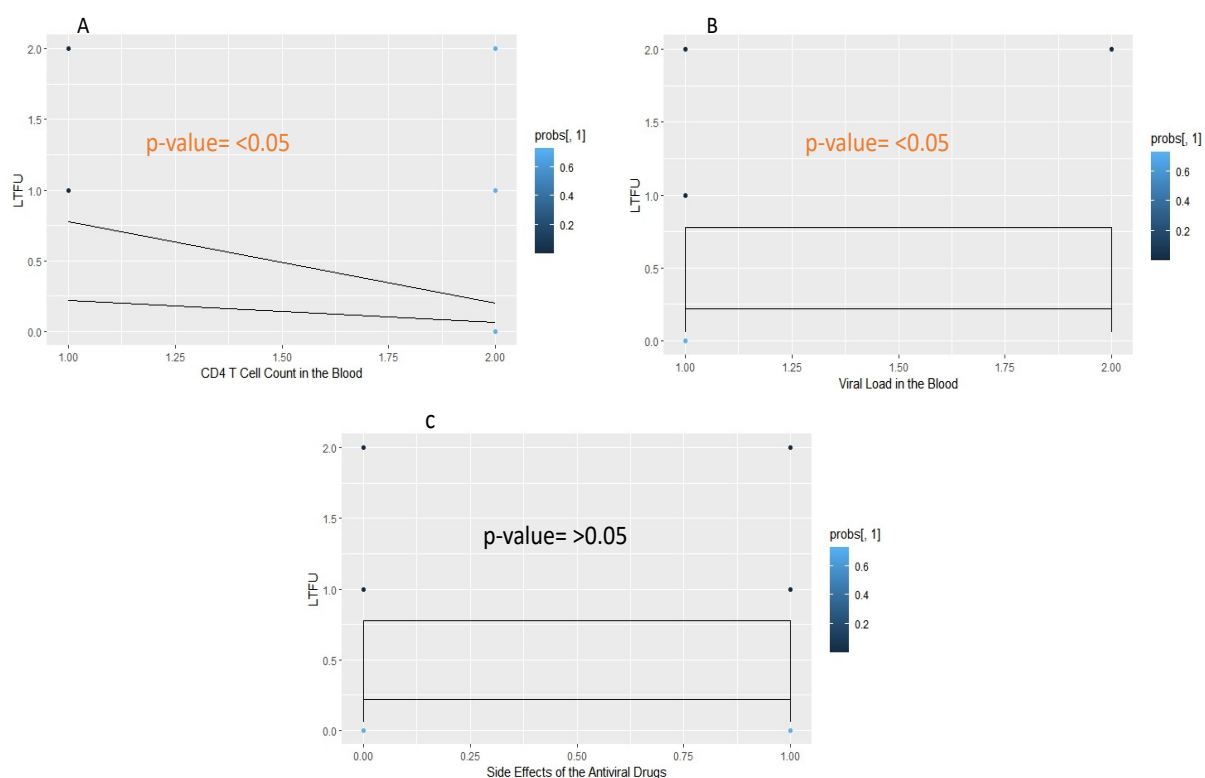


Figure 2. Correlation between clinical risk factors and LTFU. Remarks: (A) correlation between CD⁴ T-cell count and LTFU; (B) correlation between viral load in the blood and LTFU; and (C) correlation between the side effects of antiviral drugs and LTFU.

A viral load >1000 copies/mL increases the risk of LTFU by 2.79 times, which is consistent with findings in Kenya, where an unsuppressed viral load is associated with a 2.3-fold greater risk of LTFU [15]. A high viral load reflects suboptimal adherence or drug resistance, creating a negative cycle where nonadherence leads to an unsuppressed viral load, which in turn reduces the motivation to continue therapy. In Uganda, Kiwanuka et al. [16] reported that patients with a viral load >1000 copies/mL had a 68% greater probability of experiencing LTFU within 12 months. The difference from previous studies lies in the magnitude of this effect. Compared with our findings, studies in sub-Saharan Africa generally report higher ORs (OR 4-6) for low CD⁴ counts (OR 4.2), possibly because of later diagnosis and more limited access to therapy in Africa [17]. Conversely, some Southeast Asian studies, such as those in Thailand, reported lower ORs 2-3, reflecting stronger health systems and better early detection [18].

MSM had a 40% lower risk of LTFU than FSW did, a finding that differs from most of the literature. In West Africa, Eubanks et al. [12] reported that MSM had an LTFU rate of 35% compared with 22% in the general population, with stigma and discrimination as the main barriers. However, a study in India reported a similar pattern to our findings, where MSM in urban areas had better retention owing to higher health literacy and stronger community support networks [19]. FSWs face multiple barriers, including double stigma (HIV and sex work), high mobility, irregular working hours, and limited access to health services. Lujintanon [13] reported that FSWs with unsuppressed viral loads in Durban had an LTFU rate of 48%, with mobility and fear of disclosure being the main factors. In Timor-Leste, FSWs face greater social marginalization and criminalization of sex work, which hinders access to services.

The differences in our findings likely reflect the unique characteristics of the MSM population in Dili, which are connected to community organizations such as AK-P, which provide MSM-friendly services. In contrast, FSWs face greater structural barriers and weaker community support. Intervention programs need to be tailored to the specific needs of FSWs, including mobile services, flexible operating hours, and the integration of HIV services with reproductive health.

Patients ≥ 54 years old had a 21% lower risk of LTFU, which is consistent with studies in Zimbabwe and Kenya that reported that older age was a protective factor [15,20]. Older patients tend to have greater health awareness, lower mobility, and greater access to family support systems. Gray et al. [21] reported that adolescents and young adults in Liberia had an LTFU rate 2.5 times higher than that of those aged >50 years.

Marital status reduced the risk of LTFU by 26%, which is consistent with the literature that emphasizes the role of social support. In the Democratic Republic of the Congo, Mayasi et al. [22] reported that married patients had a retention rate of 78%, compared with 52% among single individuals after 24 months. Spousal support facilitates adherence through medication reminders, accompaniment to clinics, and emotional support for coping with an HIV diagnosis. However, a study in Malawi revealed a different pattern, in which marital status increased the risk of LTFU among women due to intimate partner violence and unsafe disclosure [23]. These differences underscore the importance of considering local gender and cultural context when designing interventions [24,25]. In Timor-Leste, strong family dynamics and positive spousal support appeared to contribute to better retention among married patients.

An income of $< \$115$ per month increases the risk of LTFU by 35%, reflecting economic barriers to service access. Transportation costs, loss of income during clinic visits, and the inability to purchase nutritious food hinder adherence. In South Africa, Bärnighausen et al. [26] reported that low income was associated with higher HIV incidence and poorer retention, with poverty creating a vulnerability cycle. Low education (88% of junior high school students) contributes to limited health literacy and a suboptimal understanding of the importance of adherence. Hansana et al. [27] reported that patients with low education levels had 45% adherence, whereas those with higher education levels had 82% adherence. Education-based interventions using simple language and visual methods are needed to improve patients' understanding of ART and the importance of regular follow-up. The survival rate of 97% for level 1 ART versus 3.6% for level 2 ART reflects differences in disease severity and treatment complexity. Patients receiving second-line therapy generally have a history of first-line failure, possible drug resistance, and more advanced disease stages. In Asia, Jiamsakul et al. [8] reported lower viral suppression with second-line therapy (68%) than with first-line therapy (85%), with higher mortality in the first year.

High mortality in level 2 ART indicates delayed switch therapy or suboptimal management of first-line failure. In Ethiopia, Gesesew et al. [17] reported a median time from failure detection to therapy switch of 8–12 months, a period during which patients experienced disease progression and CD⁴ decline. A more rigorous monitoring system with routine viral load testing and faster therapy switching could improve outcomes in patients with first-line treatment failure. These findings contrast with studies in high-income countries, where second-line therapy has better outcomes because of earlier access to therapy, more intensive monitoring, and more regimen options. In the United States, Calkins et al. [28] reported an 85% survival rate with second-line therapy after 3 years, reflecting the superiority of the healthcare system and access to new-generation antiretroviral drugs.

These findings underscore the importance of differentiated service delivery (DSD) tailored to patients' risk profiles. Patients with a CD⁴ count of < 200 require intensified follow-up with more frequent visits, strengthened adherence support, and proactive management of opportunistic infections. In Zambia, the implementation of DSD with fast-track refills for stable patients and enhanced care for high-risk patients has increased retention from 65% to 82% [6].

Community-based interventions, including peer support groups, home-based care, and community ART distribution points, can address barriers to accessing FSWs and highly mobile patients. Koech et al. [15] reported that community-based ART distribution in Kenya increased retention by 28% by reducing waiting times and transportation costs. Integrating HIV services with other health services, such as tuberculosis and reproductive health services, can improve efficiency and reduce stigma. Strengthened tracking and tracing systems are needed to identify patients with LTFU early and facilitate reengagement. In Uganda, Kiwanuka et al. [16] reported that phone call follow-ups within 48 h of a missed appointment reduced LTFU rates by 40%. The

use of mobile health (mHealth) technologies such as SMS reminders and digital adherence monitoring can effectively improve adherence and retention costs [29,30].

Clinical implications

The findings of this study have practical implications for optimizing HIV programs in Timor-Leste. The implementation of routine viral load monitoring every six months can identify treatment failure earlier, facilitate timely therapy switching, and prevent progression to advanced stages and mortality. A CD⁴ and viral load-based risk stratification system can allocate limited resources more efficiently by providing intensified support to high-risk patients. Economic support programs such as transportation vouchers or food packages for low-income patients can address financial barriers to accessing services. The development of one-stop shop services that integrate HIV care with other health services reduces the number of visits and increases efficiency. Strengthening peer support networks, especially for FSWs and transgender people, can address stigma and increase social support.

Limitations

The retrospective design with secondary data limits data quality and completeness, with the potential for missing data and information bias. The sample size of 150 patients was relatively small, which reduced the statistical power to detect moderate effects, especially in the subgroup analysis. The single-center study at AK-P limits the generalizability of the findings to other settings in Timor-Leste, with different population characteristics and service capacities. The definition of LTFU on the basis of a 90-day period may classify some patients who are temporarily disengaged as having LTFU. Fifth, the absence of qualitative data limits an in-depth understanding of the personal reasons for dropping out of the treatment. Future studies with prospective designs, larger sample sizes, multicenter approaches, and mixed-methods methodologies could provide more robust evidence and a comprehensive understanding of LTFU dynamics.

CONCLUSIONS

LTFU remains a barrier in HIV management in Timor-Leste, with low CD⁴ counts, high viral loads, young age, single status, and low income being the main predictors. Comprehensive strategies combining differentiated service delivery, strengthened monitoring systems, community-based interventions, and socioeconomic support are needed to improve retention. Sustained investments in tracking systems, peer support, and service integration can improve treatment outcomes and reduce HIV transmission in the community.

CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

AUTHOR CONTRIBUTIONS

Conceptualization: BVCA, JSY; Methodology: BVCA, JSY, FDNM; Software: BVCA, MDSM; Validation: BVCA, JSY, FDNM; Formal analysis: BVCA, JSY, MDSM; Investigation: BVCA, JSY, FDNM, MDSM; Resources: NCS, FDNM; Data Curation: BVCA, NCS; Writing - Original Draft: BVCA, JSY, FDNM; Writing - Review & Editing: BVCA, JSY, MDSM, NCS; Visualization: BVCA, MDSM; Supervision: JSY, NCS.

FUNDING

This study did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

ACKNOWLEDGMENTS

My thanks extend to the Ministry of Health in Timor-Leste and KOICA for enabling my education and to Yonsei University for the opportunity to grow as a Yonseian. I owe immense gratitude to my advisor, Professor Yeom Joon Sup, for his mentorship and to my committee members, Professors Jun Yong Choi and Ja Kyung Lee, for their invaluable feedback. My family, especially my mother and husband Ricardo, provided unwavering support alongside the encouragement of my friends. Finally, I would like to thank the participants of my study for their courage and honesty, which made this thesis possible.

DECLARATION OF ARTIFICIAL INTELLIGENCE USE

We hereby confirm that no artificial intelligence (AI) tools or methodologies were utilized at any stage of this study, including during data collection, analysis, visualization, or manuscript preparation. All work presented in this study was conducted manually by the authors without the assistance of AI-based tools or systems.

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