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Perceived Barriers Outweigh Perceived Benefits in Predicting Lost to Follow-Up Among HIV Patients on ART: A Health Belief Model Study in Semarang

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ABSTRACT

Background: Retaining patients diagnosed with Human Immunodeficiency Virus in lifelong treatment is critical, yet many discontinue care. This study aimed to identify factors associated with lost-to-follow-up behavior among patients receiving antiretroviral therapy in Semarang, Indonesia, using constructs from the Health Belief Model.
Methods: A quantitative cross-sectional study was conducted at a primary health center involving seventy-seven eligible respondents. Data on perceived susceptibility, severity, benefits, barriers, cues to action, and self-efficacy were analyzed using correlation tests.
Results: The findings demonstrated that perceived barriers constituted the strongest predictor of care discontinuation with strong statistical significance. Other constructs, including perceived susceptibility, perceived severity, cues to action, and self-efficacy, also showed significant moderate associations with patient retention. Conversely, the perceived benefits of treatment did not significantly influence behavior. While patients recognized the advantages of medication, structural and psychosocial obstacles such as stigma, transportation costs, and time constraints dictated their actions.
Conclusion: The negative impact of perceived barriers fundamentally outweighs the protective influence of understanding treatment benefits. Improving treatment retention requires robust preventive interventions, proactive community screening programs, and performance- and risk-based capitation models to actively dismantle systemic obstacles at the primary healthcare level, rather than solely educating patients about clinical benefits.

Keywords: ***Acquired Immunodeficiency Syndrome; Medication Adherence; Patient Dropouts; Primary Health Care; Social Stigma***

INTRODUCTION

Health is one indicator of a community or nation's well-being. The current healthy paradigm promotes a shift in people's mindset from treating illness to maintaining or preserving health to prevent

disease. Therefore, understanding of diseases and how to prevent them needs to be widely disseminated among the community. One of the health issues at the end of the 20th century that became a human catastrophe was the emergence of a disease caused by a virus, namely HIV (Human Immunodeficiency Virus), which can lead to AIDS (acquired immunodeficiency syndrome). Therapy and treatment for HIV require a long process, so patients must be diligent in attending follow-up appointments. However, many patients fail to return for follow-up within a minimum period of three months or even longer (lost to follow-up), which can adversely affect the patient's treatment process and the health care provider's monitoring of patients with HIV/AIDS.[1]

The number of people living with HIV/AIDS has continued to increase from 1990 to 2025. The latest data from the United Nations Program on HIV/AIDS in 2025 indicated that the number of people living with HIV worldwide reached approximately 40.8 million.[2] According to a report from the Indonesian Ministry of Health, the cumulative prevalence of people living with HIV in 2025 reached approximately 564,000 cases.[3] In addition, in Semarang, there were 388 new HIV cases in 2023 and 358 new cases in 2024.[4] At Dr. Soetomo General Hospital, the number of PLHIV lost to follow-up in January 2016 was 77 individuals, with various contributing factors, including death, patients still alive but lost to follow-up, and patients whose medical history could no longer be traced, most often due to incorrect addresses recorded in the ARV registry.[5]

The incidence of PLHIV lost to follow-up has increased over the years, which in turn leads to a higher risk of transmission. PLHIV who do not adhere to ARV therapy have a higher risk of transmitting the virus to others.[6] At the program level, loss to follow-up makes it difficult to evaluate the effectiveness of ARV therapy. The high incidence of loss to follow-up is influenced by multiple factors, including gender, age, education, distance from residence to health facility, knowledge, and stigma.[7]

Factors influencing loss to follow-up among HIV/AIDS patients can be explored using the Health Belief Model (HBM) framework, which posits that an individual's perception of their illness influences health behaviors. This theory focuses on an individual's subjective perceptions, including: perceived susceptibility to loss to follow-up (i.e., the conditions one would face if lost to follow-up); perceived severity of loss to follow-up (such as pain and death); perceived benefits of avoiding loss to follow-up; perceived barriers; cues to action; and self-efficacy. All of these can be influenced by modifying factors such as age, gender, educational level, occupation, knowledge, and support. These four perceptions may serve as factors affecting self-acceptance among people living with HIV/AIDS.[8]

HIV/AIDS services in Indonesia are provided free of charge, including the provision of ARVs, in nearly all health service centers, including hospitals and primary health centers (Puskesmas). ARV therapy for people living with HIV/AIDS significantly reduces mortality and morbidity, improves the quality of life of PLHIV, and enhances community expectations. Loss to follow-up among patients on ARV therapy can lead to treatment discontinuation, increased risk of death, and difficulties in evaluation and service delivery of ARV therapy.[9]

METHODS

This study employed a quantitative, correlational, cross-sectional design. The research was conducted at the Halmahera Primary Health Center in Semarang, Indonesia. The primary objective was to identify factors associated with lost to follow-up (LTFU) behavior among HIV patients on antiretroviral therapy (ART)

using constructs from the Health Belief Model (HBM), including perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy.

Total sampling was used, meaning that every eligible subject meeting the inclusion criteria was included in the study without any random selection or additional sampling technique. The inclusion criteria were: (1) HIV patients aged 18–65 years, (2) having been on ART for at least three months, (3) officially recorded as LTFU (no clinic visit or drug refill for ≥3 consecutive months), and (4) willing to provide written informed consent. Patients with diagnosed mental disorders or cognitive impairments that would prevent them from completing the questionnaire were excluded. A total of 77 respondents were enrolled, representing the entire eligible LTFU population identified during the study period.

The independent variables were the six core constructs of the Health Belief Model: perceived susceptibility, perceived severity, perceived benefits of action, perceived barriers to action, cues to action, and self-efficacy. The dependent variable was LTFU behavior, which was categorized as good, moderate, or poor based on composite scores of knowledge, attitude, and practice. Sociodemographic covariates included age, sex, marital status, education level, monthly income, occupation, distance from home to the health center, and duration of HIV diagnosis.

Data were analyzed using SPSS version 25. Descriptive statistics (frequencies, percentages, means, standard deviations) summarized participant characteristics and HBM construct distributions. Bivariate associations between each HBM construct and LTFU behavior were examined using Spearman's Rho correlation test. Correlation strength was interpreted as weak ($r < 0.3$), moderate ($r = 0.3–0.5$), or strong ($r > 0.5$). A p-value < 0.05 was considered statistically significant.

The study was approved by the Health Research Ethics Committee of Universitas Muhammadiyah Semarang (No. 680/EC/KEPK-FIKKES/UNIMUS/2026). All respondents provided written informed consent. Participation was voluntary, data were anonymized using unique codes, and confidentiality was maintained. No incentives were given.

RESULT

Table 1 presents the distribution of respondent characteristics. Regarding age, the largest proportion was the 26–35 years group, comprising 34 individuals (44.2%). This indicates that the majority of respondents were in the early productive age category. The 46–55 years group ranked second (26%), followed by the 36–45 years group (15.6%) and the 17–25 years group (13%). Respondents aged 56–65 years accounted for a very small proportion (1.3%).

Demographically, this composition shows that the study was dominated by individuals of productive age, who generally have higher levels of social and economic mobility compared to older age groups. This may have implications for patterns of health service use, treatment adherence, and health literacy.

Regarding marital status, the majority of respondents were married (59.7%). This composition suggests that most respondents were in a productive phase of life and may receive social support from their partners in undergoing treatment.

By sex, respondents were predominantly male (84.4%), while females accounted for only 15.6%. Regarding education, most respondents had higher education (44.2%) and secondary education (36.4%), indicating a reasonably good level of formal literacy. Theoretically, this condition may

contribute to the understanding of health information and adherence to therapy.

From a socioeconomic perspective, the majority of respondents (79.2%) had an income of less than IDR 3,700,000 and worked as private employees (44.2%) or laborers (28.6%). Most respondents lived within 1–10 km of the primary health center (67.5%), indicating relatively adequate geographic access to health services.

Based on the duration of living with HIV/AIDS, most respondents had been living with the condition for 2 years (39%), followed by 1 year (28.6%) and 3 years (26%). This indicates that the majority of respondents were in the early to middle stage of disease progression.

Table 1. Characteristics Respondents

Characteristics	n	%
Age		
17-25 y.o.	10	13
26-35 y.o.	34	44,2
36-45 y.o.	12	15,6
46-55 y.o.	20	26
56-65 y.o.	1	1,3
Marital Status		
Get merried	46	59,7
Unmerried	31	40,3
Sex		
Male	65	84,4
Female	12	15,6
Education		
Primary Education	15	19,5
Middle Education	28	36,4
Higher Education	34	44,2
Income		
Lower than Rp. 3.700.000	61	79,2
Rp. 3.700.000 to Rp. 7.400.000,00	16	20,8
Upper than Rp. 7.400.000,00	0	0
Occupation		
Civil Servant	7	9,1
Private Employee	34	44,2
Shopkeeper	14	18,2
Casual Worker	22	28,6
Access to Hospital		
1-10 KM	52	67,5
> 10 KM	25	32,5
Living with HIV/AIDS		
1 year	22	28,6
2 year	30	39
3 year	20	26
4 year	5	6,5

Table 2 presents the distribution of LTFU behavior among PLHIV based on the Health Belief Model (HBM) constructs: perceived susceptibility, severity, benefit, barrier, cues to action, and self-efficacy. Most HBM components showed significant associations with LTFU behavior ($p < 0.05$), except for the perceived benefit of action ($p = 0.404$).

Perceived susceptibility had a moderate positive correlation with behavior ($r = 0.521$, $p = 0.001$): respondents who felt more vulnerable to HIV-related risks tended to exhibit better behavioral quality. Similarly, perceived severity showed a moderate correlation ($r = 0.505$, $p = 0.001$); those who viewed HIV as a serious illness were more likely to have good or moderate behavior. In contrast, the perceived benefit of action was not significantly related ($r = 0.096$, $p = 0.404$), suggesting that knowing the benefits of treatment does not strongly drive behavior when other factors intervene.

The strongest predictor was the perceived barrier of action ($r = 0.652$, $p = 0.001$). Respondents who reported fewer barriers, such as stigma, transportation costs, or time constraints, demonstrated consistently better adherence. Cues to action also showed a moderate relationship ($r = 0.574$, $p = 0.001$), indicating that reminders from family, health workers, or personal routines help sustain positive behavior. Self-efficacy correlated moderately as well ($r = 0.559$, $p = 0.001$): greater confidence in one's ability to manage treatment was linked to better outcomes.

Overall, the most influential HBM components were perceived barriers, cues to action, self-efficacy, perceived susceptibility, and perceived severity,

while perceived benefits were not meaningful. Sociodemographic factors (education, income, distance) showed only descriptive trends, but HBM variables had statistically significant relationships. This implies that socioeconomic conditions play a supportive role, yet what directly determines behavior is how individuals perceive their illness, the obstacles they face, and their confidence in managing therapy. Therefore, effective interventions should focus on reducing perceived barriers and strengthening self-efficacy, rather than solely improving access or information.

Table 2. Distribution of Lost-to-Follow-Up Behavior Among PLHIV Based on the Health Belief Model

Variables	Lost-to-Follow-Up Behavior Among PLHIV						∑		*p*	*r*
	Sufficient		Moderate		Insufficient					
	n	%	n	%	n	%	n	%		
Perceived Susceptibility										
Tinggi	20	25,97	23	29,87	0	0	43	55,84		
Sedang	8	10,39	11	14,29	6	7,79	25	32,47	0,001	0,521
Rendah	0	0	0	0	9	11,69	9	11,69		
Perceived Severity										
Tinggi	15	19,48	12	15,58	0	0	27	35,06		
Sedang	12	15,58	22	28,57	6	7,79	40	51,95	0,001	0,505
Rendah	1	1,30	0	0	9	11,69	10	12,99		
Perceived Benefit of Action										
Tinggi	4	5,19	13	16,88	0	0	17	22,08		
Sedang	21	27,27	16	20,78	11	14,29	48	62,34	0,404	0,096
Rendah	3	3,90	5	6,49	4	5,19	12	15,58		
Perceived Barrier of Action										
Tinggi	11	14,29	3	3,90	0	0	14	18,18		
Sedang	17	22,08	31	40,26	4	5,19	52	67,53	0,001	0,652
Rendah	0	0	0	0	11	14,29	11	14,29		
Cues to Action										
Tinggi	23	29,87	15	19,48	0	0	38	49,35		
Sedang	3	3,90	16	20,78	9	11,69	28	36,36	0,001	0,574
Rendah	2	2,60	3	3,90	6	7,79	11	14,29		
Self Efficacy										
Tinggi	13	16,88	6	7,79	0	0	19	24,68		
Sedang	13	16,88	28	36,36	4	5,19	45	58,44	0,001	0,559
Rendah	2	2,60	0	0	11	14,29	13	16,88		

DISCUSSION

This study evaluated predictors of loss to follow-up (LTFU) among HIV patients on ART in Semarang using the Health Belief Model (HBM). The central finding is that perceived barriers exert the strongest influence on treatment discontinuation, outweighing the protective role of perceived benefits. While susceptibility, severity, cues to action, and self-efficacy showed moderate associations with retention, knowledge of treatment benefits alone did not significantly alter behavior.

The dominance of barriers reflects a core principle of the HBM: even when individuals acknowledge the advantages of therapy, structural and psychosocial obstacles can prevent adherence.[10,11] In Indonesia, stigma remains a pervasive deterrent, manifesting across societal, interpersonal, and intrapersonal levels, and consistently undermining ART retention.[12] Medication-related

challenges, particularly severe side effects, further erode willingness to continue therapy, often overshadowing the long-term benefits of viral suppression.[13] Misconceptions, such as believing ART is unnecessary when physically healthy, also accelerate disengagement from care.[14]

Despite these challenges, self-efficacy and cues to action emerged as meaningful protective factors. Patients with stronger confidence in managing therapy and those supported by family or healthcare providers were more likely to remain engaged. This highlights the importance of reinforcing patient agency and social support systems. However, interventions that focus solely on education or emphasize treatment benefits are insufficient if profound barriers remain unaddressed.[11]

This study's cross-sectional design limits causal inference, and its single-site setting may restrict generalizability. Reliance on self-reported measures introduces potential bias, particularly in sensitive domains such as stigma. The relatively small sample size (n=77) also constrains statistical power and subgroup analyses.

The findings underscore the need for barrier-focused interventions tailored specifically for primary healthcare centers (Puskesmas). To effectively apply these results, primary healthcare providers must proactively identify patients with high perceived barriers by integrating routine psychosocial assessments and screening tools during early ART initiation. Once identified, targeted interventions can be deployed. Stigma can be mitigated by normalizing HIV care within general outpatient clinics and establishing localized peer-support networks to alleviate intrapersonal and societal deterrents. Transportation barriers and associated costs can be reduced through flexible service delivery models, such as community-based medication delivery or multi-month dispensing. Furthermore, misconceptions about ART can be addressed using targeted counseling and digital-based education models to provide accessible, ongoing health literacy directly to patients. Strengthening self-efficacy through digital reminders and family involvement will further complement these efforts. At the system level, integrating community-based health screening programs, such as SEHATI, is essential. Briefly introduced innovative financing structures, such as the PRBCM (Performance and Risk-Based Capitation Model), can incentivize health centers and enhance sustainability. Ultimately, retention strategies must move beyond basic patient education toward holistic, promotive-preventive frameworks that actively dismantle these structural and psychosocial obstacles while empowering patients to remain in lifelong HIV care.

CONCLUSION

In identifying the factors associated with lost to follow-up (LTFU) behavior among HIV patients on antiretroviral therapy (ART), this study establishes that perceived barriers act as the primary determinant of treatment discontinuation, fundamentally outweighing the protective influence of perceived benefits. Although patient self-efficacy, perceived susceptibility, perceived severity, and cues to action remain vital to adherence, simply educating patients on the clinical advantages of treatment is inadequate when significant psychosocial and structural obstacles persist. Therefore, improving retention in chronic disease management requires a strategic shift toward robust promotive and preventive health interventions that actively address these systemic barriers. Achieving resilient HIV care at the primary healthcare level will ultimately require integrating proactive digital health initiatives, community-based health screening programs such as SEHATI, and innovative financing structures, such as the PRBCM (Performance and Risk-Based Capitation Model), to ensure health centers are

holistically equipped to support lifelong patient engagement.

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