



Perception and Behavior of PLWHA towards Out-of-Pocket Costs when Accessing Antiretroviral Treatment

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Abstract

Out-of-pocket costs are defined as direct and indirect costs when accessing antiretroviral (ARV) treatment at healthcare centers that aren't subsidized by the government. While ARV treatment can be accessed for free, costs for diagnostic tests, consultation, and treatment for opportunistic infections are the main factor behind the low number of People Living with HIV/AIDS (PLWHA) accessing ARV treatment post-diagnosis. This study aims to understand PLWHA's behaviors that are related to ARV treatment access based on perceived barriers to out-of-pocket costs. This study used a qualitative approach with 8 PLWHA informants and 1 healthcare worker informant that works at a care, support, and treatment (CST) clinic at a private hospital. This study was conducted for four months from July to December 2021. Results found that behaviors in accessing ARV treatment in PLWHA are influenced by their perceived seriousness of HIV, perceived barriers in the national healthcare insurance referral process, and self-efficacy. Perceived out-of-pocket cost barriers were not identified as the informants' reason for deciding to start ARV treatment or discontinue ARV treatment. This study recommends increasing the availability of clinical psychologists that can provide psychological support for PLWHA, specifically within the first 6 months of diagnosis, supplemented by peer support groups.

Keywords: ARV, out-of-pocket costs, PLWHA.

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Introduction

The number of HIV cases in Indonesia in 2020 is 41,987 cases while AIDS cases are 8,639 cases. The trend of the highest HIV and AIDS cases until 2020 is still the same, that is, most are on the islands of Java and Papua.¹ The mortality rate for HIV/AIDS cases in Indonesia is 0.99%.² Increasing People Living with HIV/AIDS' (PLWHA) access to antiretroviral (ARV) treatment is one solution to overcoming HIV/AIDS.^{3,4} People living with HIV (PLWH) require ARV treatment to reduce the amount of HIV in their bloodstream to prevent further progression, while people living with AIDS (PLWA) need ARV treatment to prevent opportunistic infections and further complications.⁵ ARV treatment is crucial for PLWHA because it is able to suppress the virus' replication rate to undetectable levels. Studies show that ARV treatment is effective in reducing HIV viral loads, and 80% of PLWH that take ARV treatment twice a day no longer have detectable viral loads after 6 months of treatment.⁶

There are 133,358 PLWHA that have accessed ARV treatment up until June 2020, which amounts to 26% of all PLWHA in Indonesia.⁷ ARV treatment can be accessed through governmental health facilities such as public hospitals and public health centers. The free distribution of ARV treatment is a part of the Voluntary Counseling and Testing or VCT program for HIV testing in Indonesia. Before receiving ARV treatment, individuals are recommended to do voluntary testing and counseling. If the tests are positive, the PLWHA will be referred for ARV treatment. Initially, ARV treatment was only given to PLWHA if CD4 levels were ≤ 350 cell/mm³. However, it is now possible for PLWHA to access ARV treatment once HIV/AIDS is detected.⁸

Out-of-pocket payments are defined as direct payments from individuals to health care providers when accessing health services. Out-of-pocket payments

serve as the main barrier behind individuals testing for an initial HIV diagnosis, PLWH that are currently undergoing treatment, and PLWH who are currently in care. Even if ARV treatment is provided for free, the costs for diagnostic tests, consultation, and treatment for opportunistic infections have a great impact on lower-income society. Out-of-pocket payments serve as a substantial proportion of health costs in all areas. In several low and middle-income countries, over 60% of health costs stem from out-of-pocket payments.⁹

One of the main factors behind the low number of PLWHA accessing ARV treatment post-HIV diagnosis is because of administrative out-of-pocket (OOP) payments.¹⁰ Antiretroviral drugs (ARVs) are provided free of charge to patients. However, PLHIV must pay for other services including VCT, medical consultations and examinations, laboratory monitoring and drugs other than ARVs. Additionally, there are opportunity costs associated with HIV care, most notably time spent away from work and travel costs. Thus, even though ARVs are free to patients, overall HIV care is not; hence, real and perceived costs might hamper access to therapy.¹¹ Therefore, this study aims to understand PLWHA's behaviors in deciding to access ARV treatment based on their perceived barriers to OOP payments for healthcare.

Methods

This research is a qualitative research with a phenomenological approach which was carried out from July to December 2021 in the city of Depok, West Java. Informants were selected purposively by dividing into two criteria, namely PLHAs who were new to ARVs (< 1 year) and those who had been using ARVs for a long time (≥ 1 year). There were 9 informants, this number was sufficient because the data was saturated or there was no new information.

The research team developed a guideline for in-depth interviews in the form of open questions consisting of 4 parts, namely implementation of support care and treatment services in health services, perceptions of out of pocket barriers, access to antiretrovirals in health services, factors that encourage access to antiretrovirals (arv), the amount of the oops fee for access to health services arv. The data collection method used in-depth interviews which were carried out between 45-60 minutes before the interviews were

conducted. The researchers gave informed consent by providing information about the research and asking the informants' willingness to participate in the research. Analysis of the results of this study was carried out deductively by using content analysis. The number of ethical approval obtained from Ethical Research Committee of Faculty of Health Sciences, State Islamic University Syarif Hidayatullah Jakarta:

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Results

Informant Characteristics

Table 1. Main Informant Characteristics

No.	Informant Code	Informant Type	Age	Sex
1.	A1	Main Informant	34 Years	Man
2.	A2	Main Informant	40 Years	Woman
3.	A3	Main Informant	27 Years	Man
4.	A4	Main Informant	39 Years	Woman
5.	A5	Main Informant	35 Years	Woman
6.	B1	Main Informant	43 Years	Woman
7.	B2	Main Informant	35 Years	Woman
8.	B3	Main Informant	31 Years	Woman
9.	C1	Supporting Informant	40 Years	Woman

The ages of informants in this study range from 27 – 43 years. The majority of informants are of productive age and are women.

but I'm afraid that things will get worse if I don't get treatment. I've been on treatment for 10 days, it hasn't been a month yet. I will go back [for treatment] on the third." (Informant B1)

Behavior in Accessing Antiretroviral (ARV) Treatment

The results of the interviews found that the informants' decisions in accessing ARV were due to their perceived seriousness toward HIV/AIDS. The informants believed without proper HIV/AIDS treatment, their conditions would become worse. Therefore, they started accessing ARV treatment once they were aware of their HIV-positive status. The following is a quote related to this finding:

"Yes, because we were referred. We are scared that if we don't get treatment... We need to get treatment, that's what the public health care center said. I don't have any symptoms yet so I'm actually kind of lazy,

A different finding was observed in another informant that stated they postponed accessing ARV treatment due to their lack of mental readiness. The informant was worried that they would implement poor treatment adherence. The following is a quoted statement from the said informant:

"I was in denial; I couldn't believe it. Even though I already knew about the results, but when I found out about my status, I surrendered to my fate. But one of my friends, she said... I actually was ready to undergo treatment. But a friend asked me to think about it first, because this [treatment] is long term, if you drop-out, the impacts will be fatal..." (Informant A3)

One informant stated that they had interrupted access to ARV due to complications in extending their national healthcare insurance. This caused the informant to become negligent and eventually forget about extending their insurance, resulting in one month off of treatment. The following is the informant's statement:

"I had stopped treatment for about a month... because of my national healthcare insurance... I stopped because I was lazy to take care of the administration. I would've had to go to the Sukamajubaru clinic first, after that I'd have to go to Simpang Depok, it would've taken a long time. I did complain, I said I was lazy to go to Simpang because it's a long wait..." (Informant B3)

Perception of Laboratory Test Costs

Informants that did not have health insurance or those who rely on personal funding perceived treatment to be relatively expensive, especially for complete blood tests, CD4 tests, and viral load tests. The following is a quote from an informant:

"It's pretty hard on us, especially for the CD4. Without national healthcare insurance, it would cost two-hundred seventy thousand rupiahs. They don't have free viral load (VL) checks. If you wanted a free VL check, the province only holds free ones once a year. At Prodia, it costs 1.3 million rupiahs. At Kimia Farma, it costs around 800 thousand rupiahs. Especially if you have to do several checks; getting a father, mother, and children tested would be heavy on our pockets..." (Informant A2)

This statement was supported by a healthcare worker at a CST clinic. It was stated that ARV initiation requires a series of lab tests. The following is a quote from the informant:

"So if you want to receive ARV, you are required to get lab tests done, such as getting complete blood tests, liver function tests, kidney function tests, hepatitis B, hepatitis C, CD4... Viral load tests are only if you have the money. Most people, well, viral load tests are generally 1.6 million

rupiahs. Many people see this as a barrier. Because, our current benchmark is viral loads, after 6 months of treatment you need to get your viral load tested. The costs are a barrier for many..." (Informant C1)

This experience differed from an informant that held national healthcare insurance. According to this informant, the costs for lab tests such as complete blood tests and CD4 tests can be acquired for free. The following is a quote from the informant:

"...Cost-wise... praise be to Allah that we have national healthcare insurance, which helps pay for CD4 tests, complete blood tests. We are greatly helped due to national healthcare insurance..." (Informant A4)

This statement was supported by a statement from a healthcare worker at a CST clinic. If a PLWHA is registered as a national healthcare insurance recipient, lab testing costs are paid for. The following is a quote from the informant:

"...If you have national healthcare insurance it's [testing] free, which is great because they will even cover CD4 testing..." (Informant C1)

It was found that viral load tests are still an out-of-pocket cost, even with national healthcare insurance. An informant stated that they had to pay for the viral load test independently at a private healthcare facility and felt that the costs were relatively expensive, even though they chose the most affordable option. The following is a quote from the informant:

"...In Depok, we don't have subsidized viral load tests yet. So we have to get tested at Prodia or Gunung Sari which is a bit expensive, around one million rupiahs and up..." (Informant A4)

A statement by a healthcare worker at a CST clinic supported this finding. The costs for viral load tests are relatively expensive and many patients choose to wait for quota for free viral load tests

instead. The following is a quote from the informant:

"Yes, since it's not covered, they don't want to get it [viral load test]. They will opt for the free option because they usually cost around 1.6 million rupiahs." (Informant C1)

Perception of Opportunistic Infection Treatment Costs

Through interviews with informants without national healthcare insurance or those who rely on personal funding, it was found that opportunistic infection treatment costs are relatively affordable. These include sexually transmitted infections (STIs) such as syphilis and gonorrhea. The following is a quoted statement from an informant:

"So far I've paid for STI treatment at a public health center, it cost around 30 thousand rupiahs." (Informant A2)

An informant with national healthcare insurance gave a different perspective. With national healthcare insurance, opportunistic infection treatment costs are completely covered. The following is a quote from the informant:

"...with national healthcare insurance, I don't have to pay for anything... Yes, praise be to Allah, all I have to pay for are photocopy fees..." (Informant B3)

Another finding is that tuberculosis treatment can be acquired for free, even if you don't have national healthcare insurance. The following is a quote from the informant:

"...the TB medicine, the red one... you only have to pay two thousand rupiahs, and that's just for registration..." (Informant B2)

This statement was supported by a healthcare worker at a CST clinic that stated that opportunistic infection treatment is relatively affordable. Tuberculosis treatment can even be

acquired for free. The following is a quote from the informant:

"...Opportunistic infections include tuberculosis; TB patients get their treatment for free. Just like how if you have national healthcare insurance, you can get contrimucseosol for free, but if you pay for it yourself, it's not too expensive. It's usually the labs that are a cost barrier, but treatment isn't." (Informant C1)

Perception of Administration Costs at Healthcare Facilities

Administration costs at healthcare facilities are relatively affordable at public healthcare centers and hospitals. This is true for informants that don't have national healthcare insurance or those that rely on personal funding. The following is quoted from the conducted interviews:

"...The good thing is that in Cipayung, you only have to pay two thousand rupiahs, which is cheap. It's just for administrative fees. At the public hospital, it costs twenty thousand rupiahs." (Informant A1)

This differed from an informant with national healthcare insurance, who stated that administration costs are fully covered. The following is a quote from the informant:

"There aren't any [costs], if you're on national healthcare insurance, the important thing is having the patience to queue." (Informant B1)

Perception of Doctor Consultation Costs

It was found that in informants without national healthcare insurance or those that rely on personal funding, the cost of a consultation with a doctor is relatively expensive. The following is a quote from an informant:

"...If you want to pay in cash at Sentra, it's so expensive. It's pretty expensive at Sentra because they have specialists, they cost around 200 thousand rupiahs." (Informant A2)

A different finding was observed in an informant that has national healthcare insurance, who stated that doctor consultation is covered. The following is a quote from the informant:

"I have national healthcare insurance, there are no costs for doctor consultations."
(Informant A5)

Perception of Transportation Costs

Several informants believe that transportation costs are not a significant barrier. This can be specifically attributed to the informants' employment status. One informant stated that transportation costs would be a barrier if they didn't have a job. The following is a quote from the informant:

"If I'm not dropped off, I would order a motorcycle from a ride-hailing app, it only costs around twenty-three thousand rupiahs. It's a good thing that I work because if I didn't, that would be a hefty cost."
(Informant A2)

Perception of Food and Beverage Costs

Informants found that food and beverage costs at healthcare facilities when accessing ARV are relatively expensive. The following is a quote from an informant:

"It's pretty expensive at the public hospital, chicken and rice costs twenty-five thousand rupiahs. With a drink, it costs thirty thousand rupiahs." (Informant A1)

Perception of Wasted Time

Several informants believe that traveling to healthcare facilities to access ARV is time-consuming. Some informants spend 45 minutes to 1-hour for travel purposes. The following is a quote from an informant:

"From my house to the public hospital it takes an hour by motorcycle, if I rode a shared taxi, I bet it'd take even longer."
(Informant A1)

A different finding was observed in another informant who perceived that traveling to the healthcare facility is not that time-consuming, which takes 10 – 45 minutes. The following is a quote from the informant:

"It only takes half an hour, it's pretty close." (Informant B3)

Otherwise, the majority of informants complain that waiting for administration when accessing ARV treatment is time-consuming. On average, waiting takes over an hour, and can even last until late in the afternoon.

"Waiting at the public hospital takes a while, especially during the pandemic since the quota is limited. Around four hours..."
(Informant A4)

Only some informants feel that they don't waste too much time waiting for administrative services. Some only spend around one hour until half a day at the healthcare facility.

"It might be because I don't use insurance so I can just wait in the 'general' line. Once I get to the public hospital, I take a number, and then I only have to wait for an hour. It's pretty fast." (Informant B2)

Discussion

Behavior in Accessing Antiretroviral (ARV) Treatment

The results of this study found that behavior in accessing ARV is influenced by individual perceived seriousness towards HIV, perceived barriers in the national healthcare insurance referral process, mental readiness, and self-efficacy. The informants' perception of out-of-pocket costs was not identified as a barrier when deciding to start ARV treatment or discontinue treatment.

The multistage referral process used in national healthcare insurance complicates administration. Individuals need to visit 3 to 4 health facilities before reaching the final referral hospital to

receive HIV/AIDS treatment. An additional 3 – 4 days, extra cost for transportation, and the individual's energy are consequential for completing administration. A qualitative study stated that one barrier faced by PLWHA when accessing ARV is the healthcare referral process. This is due to the extra time needed to obtain referral letters.¹²

Worriedness about poor treatment adherence in regards to ARV treatment is an indication of low self-efficacy. Self-efficacy is an individual's belief in their capability in organizing a series of behaviors that are needed to reach a certain goal. Self-efficacy is useful in determining whether a certain behavior can be formed or not. An individual not only considers information and beliefs about the advantages and disadvantages they might face but also consider how well they can control said behaviors.¹³

Self-efficacy has a strong correlation with mental health. An individual with good mental well-being can make decisions and feel capable of performing positive behaviors. Awareness of mental health in PLWHA is essential, specifically in women that have not performed HIV-risk behaviors before knowing their HIV-positive status. HIV/AIDS not only leaves a physical impact on PLWHA, but also on their psychosocial, economic, and educational conditions. Based on a study by Rostina and Martinis in Indonesia, PLWHA face a variety of challenges within their first 6 months of being diagnosed with HIV. At such a critical point in life, almost all PLWHA in the study felt the need for psychological and spiritual support. This kind of support can be achieved through consultation with a clinical psychologist and peer support groups. Counseling given by health workers alone is insufficient and should be supplemented by peer support groups. Peer support groups are a medium for PLWHA to share their experiences, from finding out about their HIV-positive status to their journey in empowerment. Through these

sharing sessions, PLWHA's motivation to accept their condition and start ARV treatment can be strengthened.¹⁴

PLWHA with HIV-risk behaviors are more prone to emotional instability that can impact mental health and indirectly influence their motivation in accessing ARV treatment. One important alternative is understanding their psychological root causes of emotional instability, which can be done through self-healing therapy. This type of therapy can be a solution for both vulnerable and non-vulnerable groups.¹⁴

Perception of Out-of-pocket Cost Barriers

This study found that some informants perceive out-of-pocket costs for lab tests to be relatively expensive. However, other informants that have national healthcare insurance perceive that costs for lab tests are not a barrier because they are already covered, excluding viral load tests.

Lab tests are not a prerequisite to initiating ARV therapy. CD4 and viral load tests are unnecessary when monitoring PLWHA that are receiving ARV therapy. However, lab tests are highly recommended in monitoring the safety and toxicity of the ARV treatment in PLWHA. If resources are adequate, only then are PLWHA recommended to test for viral loads to confirm the failure of therapy according to clinical and immunological criteria.¹⁵

The results of this study found that the informants' perception of opportunistic infection treatment is relatively affordable; some are even able to obtain it for free. According to a study by Susyanty, the majority of medical costs for HIV/AIDS and opportunistic infection treatment are supported by the government through national healthcare insurance or regional governments.¹⁶

The informants in this study perceive administration fees at healthcare facilities to be affordable. According to informants with national healthcare insurance,

administration fees are covered. In a study by Aji it was found that 97.1% of PLWHA are required to pay for administration fees or retribution.¹⁷ Findings from a qualitative study by Harison *et al.* found that PLWHA that do not have national healthcare insurance pay forty-thousand rupiah for administration fees.¹² Differing from a study by Susyanty *et al.*, PLWHA that have national healthcare insurance or receive facilitation from the regional government do not need to pay for treatment costs, including administration fees at healthcare facilities.¹⁶

Informants perceive out-of-pocket costs for doctor consultations are relatively expensive. However, PLWHA that have national healthcare insurance have these costs covered. According to a study by Susyanty *et al.*, doctor consultation costs are covered for those with national healthcare insurance or those that are facilitated by the regional government.¹⁶

This study found that informants' perceptions of transportation costs are relatively affordable. This is due to the informants' employed status and the availability of affordable transportation such as shared taxis and commuter rail. Sugiharti *et al.* found that one barrier to ARV treatment adherence is the cost of treatment, including transportation costs.¹⁸ Another study done by Aji found that PLWHA pay over fifteen thousand rupiahs for transportation.¹⁷

The informants' perception of food and beverage costs at the healthcare facility when accessing ARV treatment is relatively expensive. One meal can cost around thirty thousand rupiahs. In a study by Susyanty *et al.*, the biggest non-medical costs in ARV treatment are transportation and meal costs. Medical costs such as medical check-ups and ARV treatment are mostly covered by the government.¹⁶

The informants' perceptions of wasted time traveling to and waiting for administration at healthcare facilities are varied. Some informants feel like they've wasted lots of productive time because

traveling to the healthcare facility takes over an hour and administration processes can take over two hours. On the contrary, some informants feel that they haven't lost valuable time when accessing ARV treatment because the travel time and waiting for administration takes 30 minutes up to half a day.

A study by Aji found that a barrier for PLWHA in accessing ARV is the fear of being fired for frequently leaving work for treatment purposes, which can take over one hour at healthcare facilities.¹⁷ In a report by IAC and ILO, living in a different area from the hospital that provides ARV treatment can cause challenges. Once referral documents expire, they must be renewed at the primary health care facility where the individual was previously registered. It is a lengthy process that is time- and cost-consuming.¹⁹

In Depok, the city where this study was based, initiation for ARV treatment can only be done at the following hospitals: the General Public Hospital of Depok, Sentra Medika Depok Hospital, Hermina Depok Hospital, and the Universitas Indonesia Hospital. When compared to Jakarta whose public health centers are categorized as independent, PLWHA in Jakarta are able to initiate ARV treatment easier. PLWHA can start ARV initiation at almost any public health center at the district level.

It cannot be denied that some PLWHA don't want to expose their HIV-positive status and will undergo ARV treatment at hospitals that are farther away from their home. Despite this, it is still important to provide PLWHA with additional healthcare facilities where they can access ARV treatment. Increasing the amount of independent public health centers that provide ARV treatment in Depok may be a solution to resolve the barrier of wasted time and out-of-pocket costs when accessing ARV.

As we know, HIV/AIDS is a chronic condition that can be controlled by life-

long ARV treatment. Therefore, accessible healthcare is needed to monitor the continuation of ARV treatment in PLWHA. In the beginning, ARV treatment was only available at certain referral hospitals. With an increase in the number of PLWHA comes an increased need for widely accessible ARV treatment centers. It is important to bring ARV treatment centers closer to PLWHA so that all PLWHA can start ARV treatment within their nearest neighborhoods.²⁰

Conclusion

Behavior in accessing ARV treatment is influenced by the perceived seriousness of HIV, the perceived barriers in the national healthcare insurance referral process, mental readiness, and self-efficacy. The perceived barriers of out-of-pocket costs weren't identified as the informants' reason for deciding to start ARV treatment or discontinue ARV treatment. However, PLWHA that are unemployed and do not have national healthcare insurance perceive out-of-pocket costs as a barrier. The greatest out-of-pocket cost barrier for PLWHA without national healthcare insurance was found for lab tests such as complete blood tests and CD4 tests. Additionally, other perceived out-of-pocket cost barriers include viral load tests in both PLWHA that have or don't have national healthcare insurance. Wasted time for traveling purposes is also deemed as a barrier by PLWHA, which can take from 45 minutes to an hour. Waiting for administration processes takes over an hour, while some PLWHA can even spend all afternoon at the healthcare facility.

Recommendations

This study recommends increasing the availability of clinical psychologists that can provide psychological support for PLWHA, specifically within the first 6 months of diagnosis. This can be supplemented by peer support groups. This study suggests accelerating the

formation of independent public health centers in Depok and to increase the number of satellite public health care centers. Screening tools for PLWHA such as viral load tests should also be made more widely available. In addition, PLWHA who do not yet have JKN are encouraged to register or activate JKN membership.

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