



Accessibility of Children Living with HIV/AIDS to Hospitals in Ten Districts in Indonesia

Rini Sasanti Handayani^{1*}, Max Joseph Herman¹, Mujiati¹ and Siti Masitoh²

¹Center for Health Resources and Services Research and Development, Jl. Percetakan Negara 29, Jakarta 10560, Indonesia.

²Center for Public Health Research and Development, Jl. Percetakan Negara 29, Jakarta 10560, Indonesia.

Authors' contributions

This work was carried out in collaboration between all authors. Author RSH did the study conception, data acquisition and drafting the manuscript. Author MJH managed the data acquisition and interpretation, revision and final approval. Authors Mujiati and SM did the data acquisition and analysis. All authors read and approved the final manuscript.

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ABSTRACT

Background: Children living with HIV/AIDS should be treated with antiretroviral throughout life so accessibility to hospitals is one of the factors that affect treatment access. The purpose of this study was to identify the distance, travel time and the length of time required in hospitals to undergo antiretroviral therapy (ART).

Methodology: This study is a mixed methods study using a cross sectional approach. The study locations covered ten districts. Quantitative data were analyzed using the chi - square test, while qualitative data used content analysis.

Results: The study show that 38.1% children lived more than 10 km away from the hospital, 18.6% need more than an hour to get to hospital 44% need more than 4 hours to get medication (starting from enrollment up to receiving drugs).

Conclusion: There was no significant relationship between travel time and the duration of treatment with adherence to get ART. Stigma and discrimination led them to choose hospitals

*Corresponding author: E-mail: rini_11sasanti@yahoo.com, rini11_sasanti@yahoo.com;

which are located far away. To improve accessibility, central officer or NGO should inform where mobile clinics are available or help get the drugs from hospital for them.

Keywords: Accessibility; HIV/AIDS; ART; children; Indonesia.

1. INTRODUCTION

Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) is a global burden of disease (Disability Adjusted Life Years, DALYs), even in countries with low income countries occupy third place, i.e. DALYs of 58.5 million and percent total DALYs of 3.8 for all ages [1]. It is estimated that the economic costs of one year of AIDS on all households in Asia is about US \$2 billion. Any deaths from AIDS have resulted in losses of at least US \$5,000 or equivalent to 14 years of productive life calculated by the mode of US \$1 per day [2]. Although global commitment to control the HIV/AIDS pandemic has increased significantly in recent years, the virus continues to spread with alarming and increasing speed [3].

The Ministry of Health of Indonesia stated that without the accelerated program for tackling HIV, more than half a million people in Indonesia will be HIV positive by 2014. The Ministry of Health projected an increase in infected children with increasing new HIV infections in women [4]. Statistics of HIV/AIDS cases in Indonesia per September 2013 showed that the number of children infected with HIV aged less than 14 years amounted to 3,080 (3,64%) and 15-19 years to 2,908 (3,44%). Children aged less than 14 years who received ARVs reached 76.7%, according to the Directorate General (DG) of Disease Control and Environmental Health [5].

Children with HIV are a vulnerable group that needs to be protected, given their parents often have already died of HIV/AIDS so that they become the burden of family or relatives. The child protection legislation points out that every child has the right to live, grow, evolve, and participate reasonably in accordance with the dignity of humanity, as well as the protection from violence and discrimination. The State and the Government have the obligation and responsibility to provide support facilities and infrastructure in implementing child protection. A child is a person who is not yet 18 years old, including those who are still in the mother's womb [6].

Enormous advances in HIV/AIDS treatment regimen have fundamentally altered the natural history of the disease and sharply reduced HIV-related morbidity and mortality in countries where such treatments are accessible [3].

The affected populations usually have fewer material, physical, and financial resources to draw from and limited or no access to integrated health care, prevention tools and medications, thus resulting in the most severe adverse impacts. Effective and simple interventions to prevent and treat these infectious diseases exist, but their delivery to affected populations has proven very difficult due to weak health system infrastructure in many developing countries, thus the need to shift the focus from institutional care delivery to community platforms for improved accessibility. Most of these infections affect children and young adults leading to the loss of their most productive years, and some of these diseases can be fatal if left untreated [7].

Efforts to suppress HIV transmission to the child is already done by the Program on Prevention of Mother to Child Transmission of HIV (PMTCT), but the results are not encouraging. Most pregnant women with positive HIV test results do not come back so as not to get ARV therapy. This may be due to fear of the stigma and discrimination, lack of support from her husband, the family and the community; the poor quality of service received on the first visit and health workers who are not sympathetic [3]. HIV/AIDS in children can be prevented if the PMTCT program is successful.

Meanwhile, 45% of the estimated HIV infected pregnant women have received ARVs to prevent transmission of HIV to her child, increasing from 35% in 2007 and 10% in 2004. One of the causes of the increased coverage of HIV tests on pregnant women is increasing HIV testing of Provider-initiated Testing and Counseling (PITC) in antenatal clinics and delivery services, and other health services [8].

ART has to be done throughout life so *accessibility* (distance and travel time) is one of the factors that affect treatment access [9]. "Universal Access" to HIV/AIDS is a global

commitment to increase access to treatment, prevention, care and support for HIV/AIDS. Access to good treatment is characterized by the availability, affordability and acceptability of treatment services by patients [10].

The long distance and travel time can cause Children Living with HIV/AIDS (CLWHA) or their parent/caregiver reluctant to come to the health facility to obtain ART. One of the government's efforts to increase accessibility to HIV/AIDS treatment is to bring health care facility nearer to them by providing 380 hospitals that serve people with HIV/AIDS (PLWHA). The ease to get to hospitals is among the factors that may affect treatment compliance [5].

CLWHA are vulnerable groups that need to be protected by the government, for their parents often have already died of HIV/AIDS and their family or relatives have taken care of them instead. In accordance with the concept of "Universal Access" as a global commitment, then the need to identify the travel time and distance access to hospitals needed by CLWHA to get treatment of HIV/AIDS.

2. METHODOLOGY

The cross-sectional study was done using qualitative and quantitative approach in 10 districts/cities with the highest number of PLWHA, namely North and West Jakarta, Surabaya and Malang District, Denpasar and Buleleng District, Jayapura and Jayapura District, Medan and Deli Serdang District in 2015. Quantitative data were obtained through structured interviews with parents/caregivers of children with HIV/AIDS (CLWHA) age < 18 years. As many as 267 respondents were taken based on the cross-sectional sample formula with $Z = 1.96$, $P = 50\%$, $d = 0.06$ [11].

Parents/caregivers of CLWHA were contacted through coordination with hospital or non-governmental organization (NGO), given the sensitivity of the status of CLWHA then approach to the parent/caregiver is performed by case manager or NGOs that have had emotional relation. If the respondents agreed, then the interview was conducted by researchers at the time and location approved by the informant. 239 respondents out of the target samples were obtained, those who had undergone ARV therapy were 177 CLWHA, the rest had preventive therapy or not ready to undergo ARV therapy. Targeted samples cannot be reached

because many who rejected to become respondents due to stigma and fear of revealed HIV status. Qualitative data were obtained through in-depth interviews with Regional AIDS Prevention Commission, HIV Case Manager and NGOs dealing with HIV/AIDS.

3. RESULTS AND DISCUSSION

3.1 The Characteristics of the CLWHA and Their Parents/Caregivers

The primary caregiver for most of CLWHA are their parents (62,1%), senior high school educated (40,7%), unemployed/housewives (48,0%). Only 6 CLWHA (42,9%) of the 14 CLWHA aged more than 12 years old are still in school.

The characteristics of the parents/caregivers of CLWHA in this study do not generally represent the characteristics of parents/caregivers of CLWHA in the society, but only the characteristics of the CLWHA's parents/caregivers who are willing to be interviewed, because of the existence of the stigma that cause the closed nature of the population. CLWHA's parents/caregivers willing to be interviewed come mostly from the middle and low level economic class. The parents/caregivers of the upper middle-class economy and those who had a status in the community, such as government employee or officer were not willing to be interviewed.

Only 6 CLWHA (42.9%) aged more than 12 years old are still in school. This shows the magnitude of the CLWHA school dropouts or unable to enjoy the school bench and the Government has not been able to suppress the number of CLWHA dropouts. The existence of stigma and discrimination in the community made those who were already aware of their status being reluctant to school or did not have the opportunity to continue the school because of his health, or even being expelled from school. ART had to be done each month, so they had to leave school. Often, they were not frank to the school because of the fear of experiencing discrimination. From the results of the in-depth interviews with education office it can be concluded that they did not know there was a student in his working area that was suffering from HIV/AIDS. Therefore, socialization to education office and teachers must be conducted so that they understand about HIV/AIDS and

want to support their protégé suffering from HIV/AIDS to undergo ART.

The third edition of the Indonesian Compendium discussed the need for developing an inclusive and welcoming environment towards a learning, that was an environment which is accepting, caring for and educating all children, regardless of gender, physical, intellectual, social, emotional, linguistic or other characteristics such as contracting HIV/AIDS [12]. But it seems that it has not been dealt with up or reinforced by local policy, such as regulation by all districts/cities. Out of the 10 districts, only Surabaya city that already has local regulation on HIV/AIDS (which contains protection of children from HIV/AIDS infected family), though education is very important to improve the quality of life of CLWHA.

Research results of Prabhu concluded that the HIV/AIDS gives a negative impact on access to and quality of education which may be obtained by a child. Often the children of PLWHAs were forced to skip school to help meet the household needs or to help care for sick family members. The costs of a child's education are frequently also sacrificed to make ends meet. In terms of quality, in addition to that situation the child often also must face the uncomfortable conditions due to the magnitude of the stigma in society due to HIV infection suffered by one of their family members [13].

Study results by Folasire, et al. [14] about the quality of life of PLWHA have concluded that the high score quality of life on physical, psychological and environmental domains may reflect effectiveness of any interventions on PLWHA in an ARV clinic. While the relatively low score on social domain indicates lack of social support on PLWHA, marked by the presence of stigmatization and discrimination. The efforts to increase social support for PLWHA are expected to improve their quality of life.

Social protection program against the CLWHA has been done in Daerah Istimewa Yogyakarta (DIY) province, i.e. granting life guarantee that is used to help children to access health services, education services or to buy nutritious food for them [15].

The results of the in-depth interviews in ten districts/cities with the Education Office show that

just only Surabaya City has had local regulation on tackling HIV/AIDS. In article 23 it is stated that every education organizer may not refuse or expel students with HIV infected reasons or due to one of his/her family or caregiver is infected with HIV/AIDS.

Instead, interviews with district medical officers revealed a lack of knowledge of CLWHA living in the area. At the time this research was done, an only informant from the Jayapura Office of Education that affirmed the existence of a student who suffered from HIV/AIDS. Other informants said:

"... .. to my knowledge, there are no kids with HIV/AIDS, but those on drugs..."
(Education Office of Surabaya City)

". .. no children affected by HIV/AIDS, just doing a free sex and on drugs..."
(Education Office of Jayapura District)

3.2 The Distance, Travel Time, Transportation to the Hospitals and Duration of Treatment (From Registration, up to Getting the Medicine)

Table 1 shows the distance that must be travelled by the respondent from the residence to hospitals in order to obtain HIV/AIDS treatment services.

As many as 39.5% CLWHA have to travel a distance of more than 10 km to get HIV/AIDS treatment services in hospitals. Most of them were in the Buleleng District (62.5%) and the least in Jayapura District (12.5%). Nevertheless, the relationship between distance and adherence to Anti-Retroviral Therapy (ART) is statistically insignificant ($P=.42$).

One of the aspects of getting treatment is accessibility that includes distance and the travel time to the health facility [16]. To obtain Anti-Retroviral Viruses (ARVs), PLWHA face a variety of constraints, for example the location of referral hospital are far in urban areas [17]. Lawrence Green through the Precede-Proceed Model states that one's actions are influenced by predisposing factors, reinforcing factors, and enabling factors. Accessibility is included in the enabling factors [18,19].

Table 1. The distribution of the distance between the residence of CLWHA and the health facility, according to district/city

No.	District/City	N	Distance			
			< 5 km	6 – 10 km	> 10 km	Unknown
1	North Jakarta	35	9 (25.7%)	15(26.7%)	10 (17.8%)	1 (2.9%)
2	West Jakarta	21	6 (28.6%)	7 (33.3%)	8 (38,1%)	
3	Surabaya City	34	8 (23.5%)	11(32.4%)	15 (44.1%)	
4	Malang District	6	1 (16.7%)	3 (50.0%)	2 (33.3%)	
5	Denpasar City	21	5 (23.8%)	6 (17.8%)	10 (47,6%)	
6	Buleleng District	16	2 (12.5%)	4 (25.0%)	10 (62.5%)	
7	Jayapura City	6	3 (50.0%)	1 (16.7%)	2 (20.9%)	
8	Jayapura District	8	4 (50,0%)	3 (37.5%)	1 (12.5%)	
9	Medan City	22	6 (27.3%)	4 (18%)	10 (45.5%)	2 (9.1%)
10	Deli Serdang District	8	1 (12.5%)	3 (37.5%)	2 (25,0%)	2 (25,0%)
	Total	177	45 (25.4%)	57(32.2%)	70 (39.5%)	5 (2.8%)

Study results in Banjarnegara suggest that the factors that affect the utilization of community health center is the absolute distance and mileage. The greater the absolute distance and mileage the smaller the amount of utilization will be, and vice versa [14]. Another study showed higher utilizing tendencies for those whose homes were close to the health facility, though there was no significant relationship between the distance and health services utilization [16].

Study by Rahmatin using chi-square test showed the same thing, i.e. the relationship between the distance and regularity of Care, Support and Treatment (CST) visit gave *P-value* of .002. The value of *P* (.002) < .05 suggested a relation between the services accessibility with regularity of CST visit. The ease to access services such as the availability of on-site services like laboratory examination and the availability of drugs, the distance and the cost of transportation is becoming influential factors significantly on the regularity of CST visits [20].

The results of this study indicated that the distance to the health facility more than 10 km was largely found in Buleleng District (61,1%)

and Surabaya City (52,3%). While a travel time more than 60 minutes was mostly experienced by CLWHA in Malang District (50.0%).

The results of the in-depth interviews with Regional AIDS Prevention Commission, HIV Case Manager and NGOs revealed that the distance to the health facility to obtain ART was still a constraint in most of the study areas.

3.3 Travel Time to the Health Facility

The length of time needed by the respondent from their home to get to the health facility for HIV/AIDS treatment services is shown in Table 3.

Most CLWHA were able to reach a health facility in less than 30 minutes (49.2%), but as much as 18.6% of respondents had to spend more than 60 minutes to reach hospitals. The higher percentage of CLWHA with travel time from place of residence to the hospitals more than 60 minutes were mostly found in Malang District (33.3%) and no one needed more than 60 minutes in Jayapura City and Jayapura District. But again, like distance, the relationship between adherence and travel time is not significant statistically ($P = .32$, Table 5).

Table 2. The relationship between the distance to the hospitals with compliance of CLWHA to undergo ART

Distance	Compliance		Total	<i>P-value</i>
	Compliant	Incompliant		
5 kms	44 (97,8%)	1 (2.2%)	45 (100.0%)	.42
6-10 kms	54 (94,7%)	3 (5.3%)	57 (100.0%)	
> 10 kms	69 (98,6%)	1 (1,4%)	70 (100.0%)	
Total	167 (97.1%)	5 (2,9%)	172 (100.0%)	

* Distance of 5 persons unknown

Table 3. The distribution of travel time needed to the health facility based on district/city

No.	District/City	N	Travel time (min)		
			< 30	30 – 60	> 60 mins
1	North Jakarta	35	21 (60.0%)	9 (25.7%)	5 (14.3%)
2	West Jakarta	21	9 (42.9%)	7 (33.3%)	5 (23.8%)
3	Surabaya City	34	15 (44.1%)	12 (35.3%)	7 (20.6%)
4	Malang District	6	2 (33.3%)	2 (33.3%)	2 (33.3%)
5	Denpasar City	21	11 (52.4%)	5 (23.8%)	5 (23.8%)
6	Buleleng District	16	7 (43.8%)	6 (37.5%)	3 (18.8%)
7	Jayapura City	6	4 (66.7%)	2 (33.3%)	0 (0%)
8	Jayapura District	8	7 (87.5%)	1 (12.5%)	0 (0%)
9	Medan City	22	8 (36.4%)	10 (45.5%)	4 (18.1%)
10	Deli Serdang District	8	5 (37.5%)	3 (37.5%)	2 (25.0%)
	Total	177	87 (49.2%)	57 (32.2%)	33 (18.6%)

The far distance and long travel time will increase the transportation costs towards the hospital. This is in line with in-depth interview results with the NGOs and the case manager stating that part of CLWHA's parent/caregiver often chooses a health facility that is located far away for fear of exposing status to the local community. So, it can be concluded that the distance and travel time do not affect the compliance of CLWHA undergoing treatment, in contrast to the treatment of other diseases where they affect the utilization of hospitals. It still showed the existence of stigma and discrimination in the society. The results of the study by Suriyani, Nyorong and Natsir shows the same things, that there is no significant relationship ($P > .05$, $P = .79$) between accessibility and Voluntary Counselling and Testing (VCT) service utilization. In this study, the accessibility factor in the utilization of VCT is accessibility of HIV/AIDS VCT service location, especially in terms of geographical location which include mileage, travel time, waiting time, transportation model, the examination procedures for VCT [21].

The results of the in-depth interviews with HIV Case Manager and NGOs showed that travel time to the health facility for ART is still a constraint in several districts of the city, for example in Buleleng District showed that it took around 2-4 hours to the hospitals.

" There are some who needs 2 to 4 hours to reach the hospital." (HIV Case Manager of Buleleng)

To overcome this obstacle, the counselor took ARV drugs from the Community Health Center.

" The caregivers and counselors have high commitment and voluntarism by taking ARV drugs from the Community Health Center"

Socialization to eliminate/reduce stigma and discrimination among the public has been done a lot, but stigma and discrimination are still a concern of CLWHA's parents/caregivers. The study results by Yuniar, Handayani and Aryastami [22] stated that the stigma and discrimination still occurred even among health workers themselves.

Transportation barriers were specifically felt by the patient/patient's family in the city and district of Jayapura who wanted to come to a health facility. While in Jakarta, although a wide range of the means of transportation is available, having to toggle between public passages caused transportation costs to become expensive and take a long time. This is certainly having an effect on the willingness and ability of a patient/patient's family in accessing treatment for CLWHA. The difficult transportation may result in a decrease in treatment coverage, as shown on the study results on factors which influenced the *drop out* of TB treatment [23]. The results of other similar studies that those who have easy access to hospitals will have a higher treatment services (4.1%) compared to those who have difficulty in accessing hospitals (3.5%) [24].

The delay in reaching hospitals is often caused by bad road conditions, lack of transportation, and their location, so it takes a long time to be able to arrive at. On the other hand, patients with emergency cases need as soon as possible to be directly treated or handled. Indonesia is a big country with approximately 17 thousand islands,

and many of its residents still living in isolated areas with inadequate infrastructure conditions. Long distances, bad roads, and inappropriate means of transport are one of the indirect causes of late emergency case handling efforts in hospitals. In some areas in Indonesia it can even take 2 hours on the road just to reach hospitals [25]. The research results by Rosiana showed that there was no significant influence of accessibility of VCT clinics on the lost to follow-up HIV/AIDS patients with ART in Dr. Kariadi Hospital ($P = 1.21$) [26].

Solutions that have been tried to overcome the constraints of distance, travel time and transportation vary between district/city. These solutions include that the health worker/counselor/NGO to get ARVs at the health facility and then bring it to CLWHA in home visit activities, giving cash aid for transport, informing about the address and schedule of moving clinics, the existence of the Family Care to the Health Service program, and a commitment to immediately form a satellite in some community health centers and to build community health centers with VCT services. The attitude of the health worker/counselor/NGO that helps facilitate patient, according to Lawrence Green is included in the reinforcing factors for patients' compliance with ART [18,19]. Research results by Yuniar, et al. [22] revealed that a good relationship between PLWHA and the health worker is one form of social support that affect compliance to take ARVs.

The Government's commitment, namely the health officials to immediately form a satellite in

some community health centers and build those equipped with VCT is also one attempt to facilitate and maintain consistency of CLWHA to check their health status and undertake ART. The availability of hospitals and ARV drugs is one of the aspects of proper treatment services can be reached by those in need [9].

Other than to add or bring hospitals nearer, the important thing to do is continuous socialization, the giving of information and awareness to the community about HIV/AIDS to eliminate stigma and discrimination so that parents/caregivers of CLWHA do not choose a far health facility to protect CLWHA from discrimination in society.

3.4 Duration of Treatment (from Registration up to Getting Drugs)

The time required by CLWHA for treatment often gives rise to boredom in children. The time needed to undergo ART can be seen in the Table 4.

The time length of the ART beginning of registration to getting the drugs were mostly between 2–4 hours (36.2%). It took quite a long time of registering to getting drugs to undergo ART. The limited availability of ARVs dosage form for children caused it to be dispensed first, that means more time is needed. The children may become bored and school children could not attend school. But this concern turned out to be not proven. The chi square test results showed no significant relationship between the time needed and ART compliance ($P = .99$).

Table 4. The distribution of time length of registration to getting drugs according to district/city

No.	District/city	N	Time needed (hours)			
			< 2	2-4 <	< 6-4	> 6
1	North Jakarta	35	7 (20.0%)	11 (31.4%)	12 (34.3%)	5 (14.3%)
2	West Jakarta	21	4 (19.0%)	5 (23.8%)	5 (23.8%)	7 (33.4%)
3	Surabaya City	34	6 (17.6%)	14 (41.2%)	7 (20.6%)	7 (20.6%)
4	Malang District	6	2 (33.3%)	1 (16.7%)	3 (50.0%)	0 (0%)
5	Denpasar City	21	1 (3%)	8 (38.1%)	11 (52.4%)	1 (3%)
6	Buleleng District	16	2 (12.5%)	8 (50.0%)	6 (37.5%)	0
7	Jayapura City	6	2 (33.3%)	4 (66.7%)	0	0
8	Jayapura District	8	5 (62.5%)	3 (37.5%)	0	0
9	Medan City	22	5 (22.7%)	5 (22.7%)	10 (45.5%)	2 (9.1%)
10	Deli Serdang District	8	1 (12.5%)	5 (62.5%)	2 (25.0%)	0
	Total	177	35 (19.8%)	64 (36.2%)	56 (31.6%)	22 (12.4%)

Table 5. The relationship between the travel time to the hospitals with compliance of CLWHA to undergo ART

Travel time	Compliance		Total	p-value
	Compliant	Incompliant		
< 30 minutes	85 (60.7%)	2 (2.3%)	87 (100.0%)	0.32
31-60 minutes	54 (58.8%)	3 (5.3%)	57 (100.0%)	
> 60 minutes	33 (100.0%)	0 (0%)	33 (100.0%)	
Total	172 (97.2%)	5 (1.7%)	177 (100.0%)	

Table 6. The relationships between time length of ART with CLWHA's compliance to undergo ART

Duration of treatment	Compliance			P-value
	Compliant	Incompliant	Total	
Long	138 (97.2%)	4 (2.8%)	142 (100%)	0.99
Short	34 (60.3%)	1 (1.8%)	35 (100%)	
Total	172 (97.2%)	5 (1.7%)	177 (100%)	

CLWHA who undergo ART must go to hospitals at least once a month to take drugs and assessment of the ART. In this study, whenever CLWHA every month or less than one month always comes down to hospitals, then CLWHA comply with ART. Tables 5 and 6 show the relationship of the travel time and the time length of ART with the compliance of CLWHA to ART.

The results of the analysis show the travel time is not related to the compliance of CLWHA to obtain ART ($P=0.32$). In this study, the time length of ART beginning with registration up to getting drugs can be divided into two classes, i.e. long, when more than two hours and short when less or equal to two hours.

The results of the analysis indicate that the time length of ART is not related to compliance of CLWHA to come to hospitals so as to undergo ART ($P=0.99$).

The results of the in-depth interviews with NGOs and the HIV Case Manager showed that a near distance and a short travel time were not always a choice of CLWHA's parent/caregiver to determine selected means of hospitals to undergo ART.

" ... Patients do not choose the nearest hospitals neighbor for fear of being discovered by the neighborhood community" (NGO Papua)

"... ... Although there are hospitals in there, they are unwilling to seek treatment in

hospitals, afraid of revealing their status" (HIV Case Manager Papua)

4. CONCLUSION

This study identified accessibility of CLWHA to hospitals in some districts/cities in Indonesia. It can be demonstrated that stigma and discrimination are still a constraint for CLWHA to obtain ART such that they choose distant hospitals. Moreover, far distances and a long travel time is still a constraint in several districts/cities such as Malang District, Jayapura District and Jayapura City, just like lack of hospital and high cost of transportation, which is still experienced by some districts/cities such as Malang District, Jayapura District and Jayapura City. Nevertheless, travel time and treatment time are not associated significantly with ART compliance.

CONSENT

It is not applicable.

ETHICAL APPROVAL

The ethical clearance no. LB.02.01/5.2/KE.071/2014 was granted by Institutional Review Board, NIHRD, MoH of RI.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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