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# “Accessibility”: A new narrative of healthcare services for people living with HIV in the capital city of Indonesia

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## Abstract

**Background:** The progress of the fight against HIV is highlighted by significant change. HIV of the past is different from HIV of the present. Healthcare services have played an essential role in achieving the optimal goals needed to end the HIV epidemic. However, people living with HIV and those at risk of catching it (PLWH) often misunderstand the rapid growth of HIV healthcare service options.

**Objective:** This study aimed to explore the experiences of PLWH in the healthcare services featured in this study.

**Methods:** A qualitative phenomenological approach was used. Semi-structured interviews were conducted in 2017 with 12 PLWH who engaged with healthcare services in Jakarta, Indonesia, by using a purposive sampling technique. Semi-structured questions were asked which related to their experiences of using the services. Stevick Colaizzi Keen method was used to extract the thematic analysis of the study.

**Results:** The study developed four essential themes of PLWH healthcare use. They were accessibility, availability at all healthcare levels, comprehensiveness of service, and affordability.

**Conclusion:** Providing accessible healthcare services is considered essential by PLWH. It is also pivotal to helping people feel positive about the community-related healthcare services on offer. Nurse-led HIV services must maintain this progress by continuously evaluating the quality-of-service outcomes and promoting the accessibility of the services to the broader population.

## Keywords

HIV infections; health services; patient acceptance of healthcare; nursing; Indonesia

United Nations Sustainable Development Goals demand sufficient progress in ending the epidemic of AIDS and also achieving universal health coverage by providing qualified essential healthcare services (United Nations, 2016). It is vital to establish quality HIV services that offer people-centered, safe, acceptable, appropriate, effective, and efficient care for PLWH (World Health Organization, 2019a). PLWH should be engaged in a qualified diagnostic and treatment of healthcare services (World Health Organization, 2016) and must be treated with Antiretroviral Therapy (ART) (World Health Organization, 2020).

In 2019, a total of 37.9 million people around the world was living with HIV and AIDS (US Department of Health &

Human Services, 2020). Global efforts have been made to reduce this, although the progress is not sufficient. The number of people who have tested positive for HIV may be reducing globally, but this reduction is not significant enough, and prevention strategies and programs still need encouragement. There is a significant gap between actual achievement and the 2020 target. Whereas the target was to bring the number of deaths down to 500,000, it currently stands at 770,000. Furthermore, the target for the number of patients acquiring HIV was 500,000, but in 2018 1.7 million people became infected (World Health Organization, 2019b). This is why HIV prevention programs continue to be encouraged.

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Patient experience and satisfaction are important to achieve better health outcomes (Leon et al., 2019). It is notably well-known that better healthcare services for PLWH will improve patients' retention with healthcare services, maintain patients' adherence to ART, and ultimately reduce the HIV viral load (Dang et al., 2013). Discontinuation of healthcare engagement and ART adherence will have adverse HIV consequences and increase a major public health problem (Pérez-Salgado et al., 2015; Anh & Thaweesit, 2019). ART non-adherence will contribute to the failure of the immune systems of PLWH. It will also lead to an opportunistic infection that threatens the quality of life, and in the worst-case, lead to mortality (Johnson et al., 2017). ART is the key to suppressing the viral load in the bloodstream, which is important to prevention strategies. It is well known that viral suppression will reduce the risk of passing the infection to others (Siedner & Triant, 2019).

The dream of an HIV-free world is facing critical gaps and barriers, including the optimization of healthcare services. Healthcare services sometimes have the limitations of poor performance and unequal treatments (Keller et al., 2014). Program collaboration and service integration are now considered vital to health departments to ensure a comprehensive approach, but this requires inter-sectional understanding (Bernard et al., 2016). Stigma also adds challenge to improving the accessibility of healthcare. Stigma disparaging is the equal access of all to receive appropriate services at all levels and circumstances (Moradi et al., 2014).

Within the ecological and policy factors influencing HIV healthcare engagement, the availability of surveillance, testing, prevention, medical and supportive services are crucial. Access within minimal distance, clinic culture, medical home, and the availability of appointments also lead to further and better performances and increased retention of services (Mugavero et al., 2011). Negative experiences between the healthcare providers and at-risk population sometimes detracts their relationship. The feeling of awkward interaction, irrelevant questions, blaming, pettiness, poor support, and confidentiality breaches were often experienced by patients during their treatments (Stutterheim et al., 2014).

In 2018, Indonesia had a total of 640,000 PLWH; 38,000 among them had died from HIV and AIDS-related illnesses, 46,000 people were newly infected in that year. Only 51% of the suspected population knew their status, and 17% of them living with HIV were receiving treatment (UNAIDS, 2018). Obviously, the number is very far from the target and needs intensive attention to improve achievement. Jakarta and parts of West Java, as one of the megalopolis cities in Indonesia, endure significant numbers of PLWH. Jakarta and West Java are both included in the top five most popular provinces that contained people who live with HIV. In 2017, Jakarta itself had around 6,626 people who tested HIV positive (Ministry of Health of Indonesia, 2018).

Indonesia's response to the HIV epidemic is considered

modest. The escalation of stakeholders' contribution is urgent and includes the public health service (Mesquita et al., 2007). The accessibility of healthcare services has to overcome a number of barriers. Stigmatization among healthcare is often high (Risal et al., 2018). It is recognized as a predictor of discriminatory attitudes towards PLWH who engage in healthcare facilities (Harapan et al., 2013). Indonesia also experiences the policy and practice implementation disjunction that will initiate the discrimination of treatment and care (Fauk et al., 2019). As a result, PLWH encounters difficulties in engaging healthcare access; it is also hard for them to adapt to their chronic disease (Senyurek et al., 2021).

Nurses play a major role in the eradication of HIV, providing optimal services starting from preventing transmission to promoting the health and well-being of PLWH (Gilks, 2019). Nurses achieve this by implementing friendly and approachable services within health services. Nurses make mutual collaborations with the population and ensure the continuity of care being provided. Nurses circulate the information about HIV healthcare services available to the people and seek to improve the quality and accessibility of these services. Advocating comprehensive delivery must be empowered by nurse-led HIV services to bring forth patient-centered care for PLWH (Rouleau et al., 2019).

Services for the wider population and PLWH are now broad and advanced. It can be accessed on both a static basis and a mobile one. The look of healthcare services is changing hand in hand with the efforts to move forward. Implementation faces financial obstacles and the progressive needs of the population. This is regarded as the key to widening the outreach of healthcare services (Falkenberry et al., 2018). HIV service delivery is now shifting from one size fits for all approach. It will accommodate comprehensive delivery across the prevention and care continuum through differentiated care (UNAIDS, 2018). HIV care continuum of HIV has been recognized as a progression from serotesting, medical and healthcare engagement, ART treatment and adherence to the ultimate goal that is viral suppression (Kay et al., 2016). The rapid shifting and continual efforts shall be followed by progressive evaluation from all perspectives. This study aimed to evaluate the experiences of PLWH who engaged with HIV healthcare services in Jakarta, Indonesia.

## Methods

### Study Design

This research used a qualitative phenomenological method. It describes the phenomena of progressive change within HIV healthcare services. Phenomenology is a type of qualitative research that focuses on the individual's lived experiences within a specific phenomenon (Creswell, 2013). This method was used to interpret the experience of the HIV healthcare use from the service user's perspective. This study explores the experiences of PLWH who used healthcare services in

Jakarta, Indonesia. Appropriate conditions help lead towards the successful achievement of objectives (Smith, 2018).

### Participants

Participants in the study were PLWH who used HIV healthcare services in Jakarta, Indonesia. Purposive sampling is very commonly used in qualitative research. Purposive sampling allows the qualitative researcher to choose the participants and their characteristics for the study. It is essential for phenomenological study to accommodate participants who have experienced the topic of the research question. Furthermore, it will ensure the quality of the information provided by the research participants. Therefore, the criteria of participants in this study were PLWH who have engaged with HIV healthcare services and willing to share their experiences.

The number of participants was determined by reviewing available information and data saturation. Participants were recruited and selected through a designated HIV non-government organization around the city. This study evaluates the data collected from twelve participants. Saturation was achieved when no other bits of new information or issues emerged. Participants in this study were PLWH, who used HIV healthcare services, such as voluntary counseling, mother-to-child transmission programs, and methadone maintenance therapy clinics within hospitals, public health services, and prison clinics.

### Data Collection

This study was conducted in two non-government organizations (NGOs) in Jakarta, Indonesia, which provide social support and engagement for PLWH during their life with the disease. Jakarta has 38 active NGOs and foundations in handling HIV/AIDS issues. The two NGOs provided the list of participants who matched the study inclusion criteria. The selection of participants for the research was based on the types of HIV healthcare services used by the PLWH, as it was expected to enrich the data collected. The researcher made an appointment with the participant before the interviews were conducted to develop emerging environmental situations and build trust. They then set the appointment to carry out the interviews. The study was conducted between July 2016 to January 2017. The study collated the data and information through semi-structured interviews. Two experts independently authenticated the interviews. All interviews were conducted by one person (MH). The other supervisors (WW and HPS) contributed to data analysis and validated the trustworthiness of the research. The interviews were conducted in the Indonesian language and then translated by MH to the English language after data analysis.

The interviews were conducted by questioning the participants through trigger questions and follow-up questions based on the initial responses. The first question in the questionnaire was, "Could you please tell me how has your experience in using HIV healthcare services been

so far?" Then, based on the participant's answer, the interviewer asked a followed-up question such as "Would you please describe to me what do you mean by easily accessed?" or "What do you mean by it was different from what you have ever expected? Could you please elaborate on what more you expected?". Other follow-up questions were asked until the data was confirmed and verified. The interviews lasted between 45-60 minutes. The oral data were recorded through secure tape-recording, and any non-verbal communication data observed were documented in field notes. Data were stored securely within a confidential folder on the computer. The recording results were then written as a transcript in verbatim form and combined with the results of the field notes.

### Data Analysis

The stages of the data analysis process in this study used the Stevick Colaizzi Keen method (Speziale et al., 2011) by arranging the information of the interviews and transcribing the recordings into verbatim form. The data script was repetitively listened to and read to ensure the accuracy of significant information. Participant statements were marked to point out the important information relating to the objectives of the study. Finally, themes were formulated by identifying the important information, classifying it into data groups, and categorizing themes and sub-themes.

### Trustworthiness/Rigor

The researchers ensured the trustworthiness of the data and results by comparing the results with other research and ensuring the participants provided trustworthy information. Environment familiarity was also confirmed by holding pre-interview meetings and advance contact with all participants. The researcher also discussed the results with fellow researchers and supervisors (WW and HPS) with upper-level degrees of education and expertise.

The transferability of the data was conducted by ensuring that other groups of participants fully understood the research results. The findings have been read by PLWH, who were not participants in the study but still fit the inclusion criteria. This study also surveyed a variety of participants. The reliability of the data is dependent on the saturation of the participant's information by preparing questions that provide accurate answers based on the topic or issue of the study. This study also used repeat questions with an expectation of the same response to clarify and maintain the trustworthiness of the information provided by the participants. Data and results were also presented back to the participants who were involved. The researchers then showed the principles of the results of the research documentation and findings to participants who engaged in the research.

### Ethical Considerations

All activities within this research are strictly compliant with the relevant ethical guidelines and considerations. Ensuring that no one was at risk of harm or experiencing negative impacts from the research activities conducted

was crucial. By providing autonomy, beneficence, non-maleficence, confidentiality, and justice, this study was committed to protecting the participants involved. This study was reviewed by the Universitas Indonesia Ethical Council Committee and declared as ethically feasible to be conducted with ethical clearance number 0272/UN2.F12.D/HKP.02.04/2015.

## Results

### Characteristics of the Participants

There were 12 participants in this study who were PLWH that used healthcare services in Jakarta, Indonesia. The 12 participants participated voluntarily in semi-structured interviews conducted during the research process. All participants acknowledged their HIV-positive status, were open to being involved in the study, and cooperatively answered the questions during the interview. In addition, participants did not express objection or unwillingness to provide answers to any of the questions. The quoted text in this study was originally in Bahasa Indonesia and translated to English to fulfill journal requirements. The characteristic of the participants is displayed in Table 1 below.

**Table 1** Participants' Characteristics

Participant Code	Age	Education	Year of Status	Risk Population
P1	29	High School	2005	PWID
P2	30	Elementary	2006	PWID
P3	31	Junior High	2008	Heterosexual Male
P4	32	Junior High	2008	PWID
P5	34	High School	2008	Prisoner
P6	34	High School	2008	PWID
P7	34	High School	2010	Prisoner
P8	34	Bachelor	2010	Heterosexual Female
P9	39	High School	2010	PWID
P10	41	Bachelor	2014	PWID
P11	22	High School	2016	MSM
P12	31	Diploma	2016	MSM

Note: PWID= People Who Inject Drugs | MSM=Men Who Have Sex with Men

### Themes

The study developed four significant themes such as accessibility, availability at all healthcare levels, comprehensiveness of service, and affordability. Each theme is explained in the following.

#### Theme 1: Accessibility

Almost all participants stated that they had easy access to a healthcare facility. According to the participant's statement, the accessibility of the healthcare facility was determined by the proximity of the HIV healthcare facility and the transportation facilities to help them reach it. One of the participants stated that he had no complaints about

the HIV healthcare facility. His statement is documented below:

"Actually, there was no obstacle in order to reach out the facility, and the hospital was really nearby! The only problem I have is to provide a specific time to go. We didn't have to be worried; it is no big deal." (P5)

The other participant said the same thing; he said that the healthcare facilities are near his home. He also said that the facility could be reached while attending another activity. Along with fitting facial expressions, the participant stated the following:

"No, the public health center where I ran for regularly healthcare services was really close by. I can reach the place while I was going somewhere else. But the waiting was still taking some time." (P3)

Participants said that easy access to healthcare facilities was linked to the availability of transportation that they could use. There were so many transport choices in order to reach the services. Following is the relevant participant's statement:

"... the access was not too difficult for sure, it was easy! Lots of vehicles and public transportation to use." (P1)

#### Theme 2: Available at all healthcare levels

Six participants felt that the healthcare services are now available in all levels of healthcare facilities, from a primary level to a tertiary one. Participants recognized that the facilities are part of government efforts to broaden the range of available services. Two participants summarized their experience as the following:

"It depends on me, where do I want to go, which hospital do I prefer. It's completely up to me, even though I heard I could choose from the services in public health centers around me. There are so many facilities that I acknowledged, and I chose the hospital because I did not want to be recognized." (P5)

"Surprisingly, at first, I thought it only could be done at the hospital far from my house. But my peer navigator enlightened me it could also be done in the public health center near my house. It helps me a lot, you know." (P12)

#### Theme 3: Comprehensiveness of service

Participants are fully aware of their risk behaviors. It pushed them to start engaging with the healthcare services. Participants get sufficient knowledge and information from the facility, then complete serostatus checking and obtain the test results before starting ART and other behavioral therapy all in one place. Most participants admitted that all of the services for HIV care they experienced were simply done in one place. One participant stated that he felt relieved because the processes were comprehensively all in one place and helped fulfill all needs. Fluently speaking with a heavy tone, the participant expressed the following:



"I am fully satisfied with all of the services, which began with the registration., I can choose whatever name I want to respect my secrecy. They collected me with the others in a room and told us information related to HIV before asking us to express our feelings before getting the test. Some people were crying at the time, but I felt so comforted by the manner of the facilitators. I admired that. Then when I tested positive, they recommended me to start the ART. They looked after me when I disclosed my status. That was a big moment of my life, really." (P11)

The other participant felt the same thing with all the services provided by the healthcare facility. She experienced all the procedures she needed to in one place and only needed to think of her feelings at that time. With a calm tone and soft smile, she spoke as follows:

"...then they brought me to VCT. I was interviewed by the nurse, and he told me about HIV. I also ran the test there. When I came back, the doctor announced the result; I am positive. They counseled me when I reacted and checked how I was feeling, and then we planned the ART. They allowed me to ask as many questions and discuss as many things as I wanted to." (P8)

#### **Theme 4: Affordability**

Five participants stated that most of the HIV healthcare services they accessed were free of charge, but some specific services still cost them. For participants who had limited financial income, it sometimes increased their financial challenges. One participant said that the services cost him little but still caused a burden on his financial situation:

"Most of the services were free; I don't pay that much, only for the administration. I guess it might be for doctor service only. When I don't have any money, sometimes this fee was uncomfortable and hard to take." (P1)

The other participant stated that the affordability was convenient. The funding system did not burden him because it was just a small amount to cover. Compared to what he was getting, he felt it was quite cheap. With a confident tone, he said as follows:

"It was free, I guess, but there were some specific services for which I should pay, but that was okay; I think that was normal. At first, I thought it would be expensive, but it was mostly free. I feel grateful. (P10)

## **Discussion**

The themes indicated that there is a significant growth in HIV services. Easy access to the facilities mirrors the success of the healthcare system to provide accessible and quality healthcare facilities for PLWH. A study of factors associated with access to HIV healthcare services stated that HIV-positive patients preferred the nearest place in order to more easily engage with services (Lubogo et al., 2015).

Distance to care will determine the ART compliance

among the PLWH. A study in Malawi found the ART retention increased, and the possibility of loss during follow-up decreased. The range of healthcare facilities on offer influenced PLWH's decision to maintain engagement with healthcare. It also improved annual visits in ART enrollment. Distance to travel was recognized as an obstacle for PLWH (Bilinski et al., 2017). Further distance between the healthcare facility and the patient will increase the cost for PLWH, who had a lower socioeconomic status (World Health Organization et al., 2013).

The distance to travel for the affected population in rural areas was also proven to increase transmission probability. Viral suppression is the key to slow HIV transmission. Viral load suppression will never be achieved if ART compliance could not be obtained. ART compliance requires routine access to reliable and available facilities. The need to travel farther will reduce the likelihood of ART enrollment (Smith et al., 2017). The longer the distance to healthcare facilities, the lower retention in care and viral suppression (Terzian et al., 2018). The longer distance is also regarded as a barrier for healthcare service use (Tafuma et al., 2018).

The availability of healthcare services within all levels of healthcare facilities is considered an advantage. All-level facilities will broaden the range of healthcare services available to the population. Decentralization of HIV services and facilities will also expand the range that HIV services can reach. A study of decentralization of HIV healthcare services experienced by the rural communities in Canada concluded that the PLWH prefers the services to expand to all clinics and public health centers. It provides them with a friendly and well-known environment (Cunningham et al., 2014). It is also cost-effective and reduces threats (Kolawole et al., 2017). A study from Yogyakarta, Indonesia, mentioned that the availability of services keeps the process simple and is convenient to the healthcare environments. The transgender women in this study recognized the positive attitudes of the healthcare professionals and friendly social relationships on both sides (Fauk et al., 2019).

Expanding ART services delivery helps to achieve the desired outcomes of HIV eradication in low and middle-income countries. The expansion of healthcare facilities increases the potential of retention and decreases the mortality rate (Haghighat et al., 2019). The expansion of primary healthcare facilities for HIV services is also associated with the reduction of loss in follow-up and fulfills the gap of incomprehensive healthcare services (Cunningham et al., 2014). Comprehensive care is not merely one type of essential service at a time. It covers all needs and is patient-centered, i.e., the provision of test results must be followed by emotional support. A primary setting has much more time to deliver good services, and this increases patient satisfaction. The satisfaction is also linked to the attitude from reception, waiting times, HIV education, and the comfortability of the service from healthcare professionals. Satisfaction of PLWH also varies with the extent of the facilities (Odeny et al., 2013).

Delivering comprehensive healthcare services for the PLWH will optimize the healthcare continuum. It is well known that comprehensive health services will evidence the strengths of HIV healthcare services. The comprehensive services also increase patient enrolment and retention (Wroe et al., 2018). Comprehensive care also boosts the reduction of HIV transmission in the community. Healthcare services focus on prevention and education. The preventive service scale up the HIV negative and unknown status to check their serostatus (Subramanian et al., 2019).

Comprehensive healthcare services for PLWH will optimize the coordination and communication between healthcare services. Comprehensive services will unify the strategies into efficient and effective actions (Watts et al., 2019). Comprehensive healthcare services lead to universal access to ART, improving patient-centered care, and scale up the baseline of HIV testing among the population at risk and PLWH (Havilir et al., 2019).

The affordable cost of engaging healthcare services is helping PLWH to deal with their catastrophic life-changing condition. Low-cost access is believed to be the gateway to universal access for all of the population affected by HIV. Providing universal access will increase the impacts of HIV eradication efforts (Hill & Pozniak, 2016). Providing ART to all PLWH is mandatory for low and middle-income countries to achieve clinical prevention and programmatic benefit for all (Ford et al., 2018). The limitation of the study found some participants were not able to express the qualitative narration of their experience. It required the communication competency of semi-structured interviews. It was also found that there is no scoring system in validating the semi-structured questions. The importance of exploring more about HIV healthcare services literacy among PLWH is crucial.

The implication of this study can be seen that PLWH get fairly easy access to HIV healthcare services in urban and metropolitan settings. In fact, the healthcare services are now reaching the primary level and easier to access with good links to public transport. Equitable distribution of health services in urban and big cities shall be implemented in suburban areas, especially in concentrated epidemics by the government and policymakers. This study showed that the role of nursing is crucial in circulating the information of the availability of services to those PLWH.

## Conclusion

HIV healthcare services are growing stronger and continuing to progress. The old paradigm of HIV being nothing but a death sentence is fading away. Precise and accurate information is increasingly being provided to all sectors, communities, and individuals. Healthcare providers and HIV activists are recommended to promote and campaign about the new perspective of accessibility: reduced travel to facilities and less financial hardship from using HIV healthcare services, especially within urban cities.

## Declaration of Conflicting Interest

There is no conflict of interest in this study.

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## Authors' Contribution

MM contributed to developing the research, collecting and analyzing data, presenting results, and drafting the manuscript. WW and HP contributed to the study concept and design, data analysis, and manuscript development. All authors agreed with the final version of the article.

## Data Availability Statement

All data generated or analyzed during this study are included in this published article.

## Authors' Biographies

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