

The Characteristics and Perspectives of HIV-Positive Individuals among the Key and Vulnerable Populations in Surabaya, Indonesia

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ABSTRACT

There is an ongoing challenge of promoting HIV testing uptake and sustained treatment adherence among key and vulnerable populations. This study aimed to determine the characteristics and perspectives of HIV-positive individuals among the key and vulnerable populations in Surabaya, Indonesia. This was a cross-sectional study with a mixed-methods in HIV-positive key and vulnerable populations. Clinical and laboratory data were obtained from medical records. A questionnaire collected data on sociodemographic characteristics, behavior, sexual practices, cognitive function, depression, and quality of life. The study indicated that 52.8% of participants were HIV-late diagnosis with several characteristics: being male ($p=0.021$); having lower BMI ($p=0.001$), lower lymphocyte count ($p<0.001$), poor knowledge of HIV cause ($p=0.016$), low quality of life on physical health ($p<0.001$), psychological health ($p=0.020$), and social relationship ($p<0.001$); lower cognitive function ($p<0.001$); and moderate to severe depression ($p<0.001$) than non-HIV late diagnosis. The interviews revealed that most participants hid their HIV status from their families and experienced stigma. NGO staff played a crucial role in educating, encouraging, and assisting them in accessing relevant health services. More than half of the participants were diagnosed late. Improving community-based programs, expanding mental health resources, and reducing stigma are the key strategies for enhancing HIV-related outcomes.

Introduction

Up to June 2024, 598,271 HIV cases and 168,263 AIDS cases were reported by all 38 provinces and 512 of 514 districts in Indonesia (Ministry of Health of the Republic of Indonesia, 2024). Most HIV cases (63.0%) were in males. HIV transmission was mostly by heterosexual contact (28.1%). However, there was a shift in HIV transmission by homosexual contact reported in 2010

compared to 2022. Homosexual contact only accounted for 3.0% of the 2010 report and increased to 18.7% in the 2022 report (Ministry of Health of the Republic of Indonesia, 2022).

The HIV prevalence in the general population in Indonesia is approximately 0.3%, varies in each province, and is tenfold higher in Papua Province. As of June 2024,

Indonesia was still lagging behind the 95-95-95 UNAIDS target, with 70% - 62% - 42% achievement, meaning: approximately 70% of people living with HIV/AIDS (PLWHA) knew their status; 62% of those positive were on antiretrovirals (ARV), of whom 42% were virally suppressed (Ministry of Health of the Republic of Indonesia, 2024). The forefront of HIV testing is conducted in public health centers (puskesmas), prenatal clinics, tuberculosis clinics, mobile voluntary counseling and testing (VCT) in entertainment places, and through targeted campaigns in key populations. Yet, the 2018-2019 IBBS in key population in Indonesia reported only 72.0% of transgenders (TG), 59.0% of men who have sex with men (MSM), 42.0% of female sex workers (FSW), 67.3% of injecting drug users (IDU), and 7.8% of high-risk men (HRM) have ever had an HIV test (Wisaksana et al., 2019).

HIV late diagnosis, people diagnosed with a CD4 count below 350 cells/mm³ blood or with an AIDS-defining event, is one of the challenges faced by HIV/AIDS prevention and control programs (Collins et al., 2022). HIV late diagnosis might have a worse prognosis, less benefit from antiretroviral therapy (ART), and increased risk of transmission. The prevalence of HIV late diagnosis varies worldwide. In 2020, 55% of HIV diagnoses in South Africa were late diagnoses. The prevalence was 42%-63% in the UK. In 2019, 20%-34% of HIV diagnoses in the US were late diagnoses (Collins et al., 2022). In Indonesia, more than 50% of HIV diagnoses were made when patients had already had AIDS (Riono & Challacombe, 2020). Therefore, NGOs play a crucial role in HIV prevention and intervention by directly reaching out to vulnerable populations, offering essential

services, and advocating for policy changes. They address stigma, provide psychosocial support, and partner with government agencies and other stakeholders (Jacobi et al., 2020; Kimera et al., 2020).

This study aimed to determine the characteristics and perspectives of HIV-positive individuals among the key and vulnerable populations in Surabaya, Indonesia.

Methodology

Study designs and participants

This study used a cross-sectional design with a mixed-methods approach (Creswell, 2018). The inclusion criteria were newly diagnosed HIV-positive key and vulnerable populations who had not received ARV, aged 17 years and over, could read and understand the Indonesian language, and agreed to participate voluntarily in the study. The exclusion criteria were those with cardiac failure symptoms, mental disorders, or malignancy.

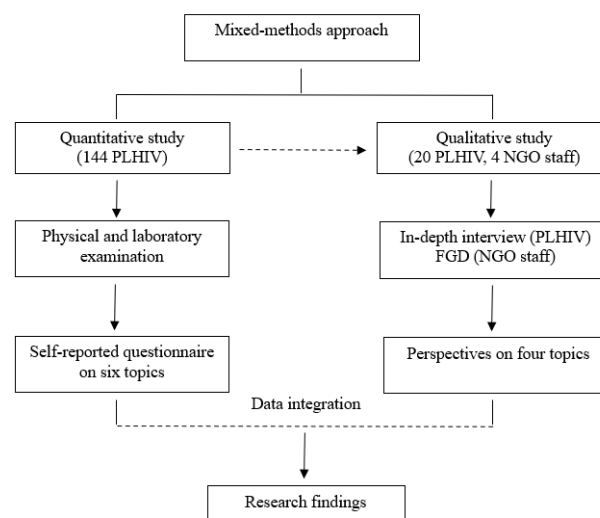


Figure 1. Mixed-methods approach

The sample size was calculated based on the cross-sectional study sample size formula with a categorical outcome (Sharma et al., 2020). One hundred and forty-four

study participants were recruited using purposive sampling from 168 newly diagnosed HIV-positive key populations from March to December 2019 from mobile VCT, public health centers, transgender societies, and several non-governmental organizations (NGOs) working on HIV and AIDS in Surabaya and Sidoarjo, East Java Province, Indonesia. Four patients of the 168 newly diagnosed HIV-positive key population were not eligible due to exclusion criteria, and 20 patients were excluded due to incomplete data on cognitive function, quality of life, and depression. This study categorized key and vulnerable populations into five groups: spouses of the key population (KP-sp), female sex workers (FSW), high-risk men (HRM), men who have sex with men (MSM), and transgender women (TG-w). The KP-sp mainly consisted of spouses or partners of HRM and MSM. FSW consisted of direct and indirect FSW. Direct FSWs were females who openly offered sex at legal or illegal prostitution. Indirect FSWs were females who worked at particular jobs and indirectly offered sex at entertainment places, such as massage parlors, bars, or karaoke (Wisaksana et al., 2019).

Data collection

All study participants underwent history taking and physical examinations, including body mass index (BMI), which was calculated by $\text{body weight (kg)} / \text{height (m)}^2$, and the classification was based on the Asian population. Further, the participants also underwent several laboratory tests. The absolute CD4 cell count was measured with immunofluorescence analysis using flow-cytometry BD FACS CaliburTM count. The laboratory tests were performed at a teaching hospital in Surabaya.

This study employed structured questionnaires at the first visit to collect data on demographic characteristics, sexual practices, and knowledge. The HIV knowledge included causes of AIDS, HIV transmission, HIV prevention, and awareness while having sex without using a condom. Cognitive function was measured using the Montreal Cognitive Assessment – Indonesian version (MoCA-INA), which had been validated (Panentu & Irfan, 2013). MoCA-INA consisted of visuospatial/executive, naming, memory, attention, language, abstraction, delayed recall, and orientation. Depression was measured using the Indonesian version of the Beck Depression Inventory-II (BDI-II), which had been validated (Ginting et al., 2013). Quality of life was measured using the validated Indonesian version of the World Health Organization Quality of Life Brief Version (WHOQOL-BREF) (Muhammad et al., 2017).

Out of the 144 PLWHA participants, 20 took part in in-depth interviews. Additionally, four staff members from four separate NGOs involved in HIV/AIDS participated in a focus group discussion (FGD). The interviews explored three main topics: participants' emotional reactions upon learning their HIV status, the types of support they received, experiences with stigma and or discrimination, and their plans for the future. The FGD focused on the training they had undergone and the challenges they faced in their work.

Data analysis

Study participants were categorized into late and non-late diagnoses. HIV late diagnosis is defined as a person first diagnosed with HIV with a CD4 count below 350 cells/mm³ blood or with an AIDS-

defining event, regardless of the CD4 cell count (Collins et al., 2022). On the contrary, HIV non-late diagnosis is a person first diagnosed with HIV with evidence of recent infection (i.e., being diagnosed during seroconversion). Evidence of recent infection is based on laboratory evidence of recent infection, a last negative HIV test within 12 months of HIV diagnosis, or clinical evidence of acute infection (Collins et al., 2022).

The normality of the distribution for continuous variables by late and non-late diagnosis was tested using the Kolmogorov-Smirnov test, which showed that quality of life (QoL) in physical health and current age were normally distributed; therefore, these variables were presented as mean (SD). The differences in the mean of the normally distributed variables across late and non-late diagnosis categories were analyzed using two independent samples t-tests (Mishra et al., 2019). BMI, age at the first time having sex, QoL in psychological health, social relationship, and environment were not normally distributed; therefore, these variables were presented as median (Quartile 1 - Quartile 3). The non-normally distributed variables across late and non-late diagnoses were analyzed using the Mann-Whitney U test (Mishra et al., 2019). The cut-off score for cognitive function was 26 and was categorized into two categories: poor (<26), and good (≥ 26) (Panentu & Irfan, 2013). The depression score was classified into four categories: minimal (0-13), mild (14-18), moderate (20-28), and severe (≥ 29) (Ginting et al., 2013). The analysis for QoL was carried out according to WHO guidance: domain 1 (physical health), domain 2 (psychological health), domain 3 (social relationships), and domain 4 (environment)

(Muhammad et al., 2017). The differences in categorical variables by late and non-late diagnosis were analyzed using Kendall's Tau tests (Mishra et al., 2019). All analyses were performed using IBM® SPSS® for Windows® version 25.0.

The qualitative data analyses include familiarization with the data, transcribing and checking, reading between the lines, coding, theming, synthesizing, and reporting the findings (Creswell, 2018).

Ethical approval and consent to participate

The purpose, procedure, conditions, and ethical considerations of the study were explained beforehand to the study participants. Written consent was obtained from each study participant who agreed to participate voluntarily. The research ethics approvals were acquired from the Human Research Ethics Committee at Hang Tuah University (No. 05/M/DU/KEPUHT/I/2019) and Dr Ramelan Central Naval Hospital, Surabaya (No. 66/EC/KERS/2019).

Results and Discussion

Quantitative study

Of 144 study participants, 60 (41.7%) were females, and 84 (58.3%) were males. Of all study participants, 11.1% were KP-sp, 36.1% were FSW, 19.4% were HRM, 23.6% were MSM, and 9.7% were TG-w. Subset analysis revealed that the two youngest study participants, aged 19 years, were FSW and MSM, while the oldest, aged 62, was an FSW.

Table 1 depicts that 76 (52.8%) of all study participants were late diagnoses, and 68 (47.2%) were non-late diagnoses. Moreover, 48 (33.3%) of study participants attended elementary school, 26 (18.1%) attended junior high school, 60 (41.7%) attended senior high school, and only 10 (6.9%) had a university degree.

Most study participants (43.1%) worked in the private sector, non-entertainment, 33.3% worked in entertainment areas, 15.3% did not work, 5.6% worked in the armed forces, and 2.8% worked as civil servants. Most study participants (40.3%) had never been married,

33.3% were married, and 26.4% had divorced or his/her spouse had died.

There was a significant difference in sex between late and non-late diagnoses ($p = 0.021$). Still, no significant difference was found in age, ethnicity, level of education, type of current employment, type of key population, and marital status.

Table 1. Sociodemographic characteristics [n (%), mean $\pm$ SD].

	Late n = 76	Non-late n = 68	p-value
Age (years) ^a	33.9 $\pm$ 9.0	34.3 $\pm$ 10.9	0.886
Sex ^b			0.021
Female	22 (28.9%)	38 (55.9%)	
Male	54 (71.1%)	30 (44.1%)	
Ethnicity ^b			0.834
Javanese	70 (92.1%)	60 (88.2%)	
Other	6 (7.9%)	8 (11.8%)	
Level of education ^b			0.139
Elementary school	16 (21.1%)	32 (47.1%)	
Junior high school	16 (21.1%)	10 (14.7%)	
Senior high school	38 (50.0%)	22 (32.4%)	
Academic/university	6 (7.9%)	4 (5.9%)	
Types of current employment ^b			0.248
None	14 (18.4%)	8 (11.8%)	
Arm forces and civil servants	10 (13.2%)	2 (2.9%)	
Entertainment	18 (23.7%)	30 (44.1%)	
Private sector non entertainment	34 (44.7%)	28 (41.2%)	
Type of key population ^b			0.269
KP-sp	8 (10.5%)	8 (11.8%)	
FSW	22 (28.9%)	30 (44.1%)	
HRM	22 (28.9%)	6 (8.8%)	
MSM	18 (23.7%)	16 (23.5%)	
TG-w	6 (7.9%)	8 (11.8%)	
Marital status ^b			0.408
Never married	30 (39.5%)	28 (41.2%)	
Married	30 (39.5%)	18 (26.5%)	
Divorce/death	16 (21.1%)	22 (32.4%)	

^a Two independent samples t-test, ^b Kendall's Tau test, spouses of the key population (KP-sp), female sex workers (FSW), high-risk men (HRM), men who have sex with men (MSM), and transgender women (TG-w).

Table 2 showed a significant difference in BMI across late and non-late diagnosis categories ($p = 0.001$). The mean lymphocyte count was also significantly

different between late and non-late diagnoses ($p < 0.001$).

Of the HIV-related knowledge, the cause of HIV was significantly different

between late and non-late diagnoses ($p = 0.016$). However, there was no difference in knowledge of HIV transmission, HIV prevention, and awareness of HIV while condomless. Who introduced participants to a VCT was found to be a significant difference between late and non-late diagnoses ($p = 0.017$).

Based on the WHOQOL-BREF guideline, all domain scores should be between four and 20 after transformation and computation. The difference in QoL score was found in the physical health ($p < 0.001$), psychological health ($p = 0.020$), and social relationship ($p < 0.001$) domains.

Overall, 61.1% of study participants showed a lower cognitive function (<26) based on MoCA-INA, in which the majority were from the late diagnosis group. Subset analysis indicated that all participants' lowest overall MoCA-INA score was verbal fluency (words beginning with a particular letter) and the alternative trail-making. In contrast, the best overall score was found in orientation. In this study, depression was significantly different between late and non-late diagnoses ($p < 0.001$).

Table 2. Clinical finding, quality of life, cognitive function, HIV knowledge, and depression [n (%), mean $\pm$ SD, median (Q1-Q3)].

	Late (n=76)	Non-late (n=68)	p-value
BMI (kg/m ²) ^c	21.7 (18.5-23.8)	24.8 (21.6-27.2)	0.001
Hemoglobin (g/dL) ^c	13.9 (11.3-15.1)	13.7 (13.1-14.9)	0.697
Lymphocyte (10 ³ /μL) ^a	1.6 $\pm$ 0.7	2.7 $\pm$ 0.9	<0.001
HIV-related knowledge:			
Cause of AIDS ^b			0.016
Correct	12 (15.8%)	28 (41.2%)	
Wrong	64 (84.2%)	40 (58.8%)	
HIV transmission ^b			0.529
Correct	18 (23.7%)	12 (17.6%)	
Wrong	54 (76.3%)	54 (82.4%)	
HIV prevention ^b			0.485
Correct	16 (21.1%)	10 (14.7%)	
Wrong	60 (78.9%)	58 (85.3%)	
Awareness of HIV risk while condomless ^b			0.067
Yes	40 (52.6%)	50 (73.5%)	
No	36 (47.4%)	18 (26.5%)	
Who introduced you to a VCT? ^b			0.017
Myself, family, spouse, partner	6 (7.9%)	6 (8.8%)	
NGO, peer educator, pimp	40 (52.6%)	54 (79.4%)	
Health workers	28 (36.8%)	4 (5.9%)	
Other	2 (2.6%)	4 (5.9%)	
Quality of Life			
Physical health ^a	44.8 $\pm$ 8.3	53.9 $\pm$ 8.9	<0.001
Psychological health ^c	41.7 (36.5-45.8)	45.8 (41.7-55.2)	0.020
Social relationship ^c	33.3 (25.0-50.0)	66.7 (58.3 – 75.0)	<0.001

Environment ^c	40.6 (36.7-50.0)	46.9 (37.5 – 50.0)	0.121
Cognitive function ^b			<0.001
< 26	60 (78.9%)	22 (32.4%)	
≥ 26	16 (21.1%)	46 (67.6%)	
Depression ^b			<0.001
Minimal (0-13)	2 (2.6%)	30 (44.1%)	
Mild (14-19)	12 (15.8%)	22 (32.4%)	
Moderate (20-28)	32 (42.1%)	10 (14.7%)	
Severe (≥29)	30 (39.5%)	6 (8.8%)	

^a Two independent samples t-test, ^b Kendall's Tau test, ^c Mann-Whitney U test, NGO= non-governmental organizations, VCT= voluntary counseling and testing.

Table 3 showed no significant differences in high-risk behavior and sexual practices between late and non-late diagnoses, including age at the first time had sex, ever smoked, ever drank alcohol, ever

used narcotics, ever diagnosed with sexually transmitted infection (STI) before HIV-positive, and the number of sexual partners before HIV-positive.

Table 3. High-risk behavior and sexual practices [n (%), median (Q1-Q3)].

	Late (n=76)	Non-late (n=68)	p- value
Age at the first time had sex ^c	19.0 (15.0-23.0)	17.5 (15.0-20.0)	0.219
Ever smoked ^b			0.487
Yes	42 (55.3%)	32 (47.1%)	
No	34 (44.7%)	36 (52.9%)	
Ever drank alcohol ^b			0.863
Yes	32 (42.1%)	30 (44.1%)	
No	44 (57.9%)	38 (55.9%)	
Ever used narcotics ^b			0.580
Yes	6 (7.9%)	8 (11.8%)	
No	70 (92.1%)	60 (88.2%)	
Ever used a condom before HIV diagnosis ^b			0.672
Yes	4 (5.3%)	6 (8.8%)	
No	72 (94.7%)	62 (91.2%)	
Ever diagnosed with STI before HIV-positive ^b			0.663
Yes	26 (34.2%)	20 (29.4%)	
No	50 (65.8%)	48 (70.6%)	
Number of sexual partners before HIV-positive ^b			0.489
1	14 (18.4%)	12 (17.6%)	
2-10	22 (28.9%)	10 (14.7%)	
11-20	12 (15.8%)	12 (17.6%)	
>20	28 (36.8%)	34 (50.0%)	

^b Kendall's Tau test, ^c Mann-Whitney U test, STI= sexually transmitted infection.

Qualitative study

Characteristics of study participants

Of the 20 PLWHA who participated in in-depth interviews, two were KP-sp, six were FSW, two were HRM, five were MSM, and five were TG-w. Moreover, four staff members from different NGO joined the FGD.

In-depth interviews

1. Participants' emotional reactions upon learning their HIV status

Most participants were shocked upon learning their HIV status. "After my husband died, I got a test, and I was very shocked because I was positive" (Mrs. M, a 37-year-old KP-sp). An FSW stated, "It is not unusual for us to get syphilis or gonorrhea infection. We know that it is a consequence of our work. It is acceptable. We just have to buy medicine or go to a clinic to get medicine. But getting HIV is a different situation" (Miss N, a 29-year-old FSW). A participant expressed, "Oh my God, I felt like the sky was going to fall" (Miss F, a 26-year-old TG-w).

2. The types of support they received

A participant stated, "Last year, my parents were very upset with me when they learned that I am gay. They kicked me out of the house. But when they learned that I was positive, they finally supported my treatment" (Mr. T, a 28-year-old MSM). Another participant stated, "My husband asked me to do a massage plus, because he lost his job and we need money to live. He regretted his decision. Now he supports me to be healthy" (Mrs. S, 42-year-old KP-sp).

3. Experiences with stigma and or discrimination

All study participants experienced stigma and or discrimination either from their family, friends, or colleagues. A KP-sp stated, "My husband died six months ago and was buried with special treatment that made my family and neighbors find out he was an AIDS patient. They stayed away from me. Some asked me whether he had sexual relationships outside marriage and warned me that I might get infected" (Mrs. M, a 37-year-old KP-sp). Another FSW stated, "If I get an HIV infection, it will ruin my life. I will likely lose many friends and guests" (Miss S, a 26-year-old FSW).

To prevent stigma, some participants intended to remove the labels from their ARV bottles, hoping their family and friends would assume they were taking vitamins instead. Some study participants also reported that they lost their jobs and friends due to their HIV diagnosis. One MSM participant shared that some of his coworkers refused to use a cup he had previously used, while a TG-w participant reported being asked to resign from her job as a hairdresser after her HIV diagnosis.

4. Their plans for the future

While many of the study participants knew that HIV could be prevented by using a condom, the majority of them did not wear a condom during sexual intercourse before they were diagnosed with HIV. Further, after they have been diagnosed with HIV, the majority of them continued having sexual transactions without using a condom. They knew the risk, but some of them argued that they had to survive by having sexual transactions. One participant expressed, "Everyone will die eventually, even those without HIV. But I need to survive and provide for myself. If I don't work, who will support me financially?" (Miss T, a 31-year-

old TG-w). A participant stated, “I am not going to take the ARV. I don’t want my skin to become dark or spotty” (Mr. Y, 32-year-old MSM).

Focus group discussion

The training they had undergone and the challenges they faced in their work

All participants had been employed at their respective NGOs for over three years, and each NGO was affiliated with international foundations. They have undergone various training, including collaboration with health service institutions, outreach, counselling, community education, and mentoring. “I always work with a public health center in preparing and implementing mobile VCT. I am a peer educator. I am also HIV-positive. I always remind my friends to get tested, but some still refuse” (Ms. N, 28-year-old FSW). “We just need to keep supporting them, so that we can help scale up access to related health services” (Ms. R, 26-year-old FSW). “I once helped the doctor at a public health center to look after the corpse of a PLWHA, because his family abandoned him” (Mr. P, 33-year-old MSM).

Discussion

As of June 2023, Indonesia’s progress towards the 95-95-95 UNAIDS target was 77% - 40% - 16%: 77% of all PLWHA know their HIV status, 40% of all people with diagnosed HIV infection receive sustained antiretroviral therapy, and only 16% of all people receiving a six-month antiretroviral therapy have viral suppression. Globally, it remained a significant public health problem, with a prevalence of approximately 34-72% across Asia (UNAIDS, 2022). Our study supported the report, in which 56.9% of the newly diagnosed HIV-positive key population were HIV-late diagnosis. A prior

study reported that not attending formal education, poor HIV knowledge, and internalized stigma were determinants of HIV late diagnosis (Beyene & Beyene, 2015; Maretalinia et al., 2023). Late diagnosis of HIV leads to late access to ART, which could jeopardize health and escalate transmission, morbidity, and mortality (Collins et al., 2022).

Most study participants were introduced to VCT clinics by NGO, peer educator, or pimp. In contrast, a small percentage of participants visited VCT clinics with their awareness, suggested by family, spouse, or partners. In addition, more participants in the late diagnosis group were introduced to VCT clinics by health workers during mobile VCT or referral from doctors, thus they were already late when they were diagnosed as HIV positive. The mobile VCT enables health workers and NGOs to carry out health services outside the health care facilities, by visiting key populations in their high-risk places for contracting HIV, such as spas, massage parlors, karaoke places, pubs, motels, and hotels (Wisaksana et al., 2019).

Prior studies reported that being male was correlated with HIV late diagnosis, which could be related to the role of masculinity norms as a way of maintaining a sense of normality and preserving their reputation in society (Nabikande et al., 2022). Our study also found that the median BMI was lower in HIV late diagnosis. Prior studies indicated that higher BMI was correlated with slower HIV progression, and there was a linear increment of BMI over the treatment time (Baraki et al., 2019).

Our study indicated that the majority of participants had poor HIV knowledge. Moreover, there was a contrast between the knowledge and sexual practices of study participants. While some of our study

participants knew that HIV could be prevented by using a condom, the majority of them did not wear a condom during sexual intercourse before they were diagnosed with HIV. Further, after they had been diagnosed with HIV, most of them kept having sexual transactions. Studies indicated that poor knowledge about HIV significantly increases the risk of infection, particularly among vulnerable groups such as women. In many settings, women are at heightened risk of contracting HIV from their husbands or intimate partners, often due to limited awareness and lack of access to accurate information about HIV transmission and prevention. Enhancing knowledge and awareness is essential, as it empowers the vulnerable population to protect themselves and others, encouraging them to seek HIV testing as a preventive measure (Maretalinia et al., 2023). Another study reported that knowledge level was one of the factors in acquiring TB as an opportunistic infection among PLWA (Hulu et al., 2024).

Late diagnosis of HIV typically had a poorer immune recovery, higher disease burden, higher healthcare costs, and increased risk of transmission. Previous studies estimated the possible increase of HIV transmission from the key population to the general population in Indonesia, and the spouse or partners of the key population might serve as the bridging of the epidemic, as they rarely used a condom, the possibility of mother-to-child transmission, and stigma related to gender issues and HIV status disclosure (Riono & Challacombe, 2020). A survey carried out in 2018 in Bandung, the capital city of West Java Province, revealed that around 0.5% of adolescent FSW, 3.0% of adolescent and young TG-w, and alarmingly, 30.0% of adolescent and young MSM were HIV-positive. The young key population was

reluctant to visit healthcare facilities; therefore, they knew their HIV status after being included in the mobile VCT and might have already transmitted HIV to their sexual partners. While most HIV infections in Indonesia are transmitted through heterosexual contact, there has been an alarming increase in HIV transmission via homosexual contact, especially among young people (Wisaksana et al., 2019).

Late diagnosis of HIV could be associated with an increased risk of cognitive impairment, which indicates high viral replication in the central nervous system (CNS). A comprehensive evaluation of PLWHA using the neuropsychological assessment batteries with high sensitivity and specificity would be beneficial. Still, it might need a longer time and may not always be feasible for everyday practice. MOCA is an attractive screening tool related to its single page, short time to complete (around ten minutes), and it can assess multiple domains of cognitive functions, adapted to several languages and cultural settings. A prior study reported that MoCA was sensitive to detecting mild cognitive impairment in HIV-infected individuals, even though several factors, such as education, older age, and advanced HIV clinical staging, might influence its normative value (Rocha Filho et al., 2019). In our study, for those with the possibility of neurocognitive impairment, the majority had a late diagnosis.

Numerous studies reported the prevalence of depression in HIV-infected individuals that was higher than in the general population. Depression was associated with immunologic failure, poor treatment adherence, and disease progression. Depression is a persistent mood disorder characterized by feelings of sadness,

loss, anger, and frustration that interfere with daily living. Stigma, discrimination, income, chronic illness, lack of social support, and violence were associated with depression among PLWHA (Deshmukh et al., 2017; Tao et al., 2018). Ideally, depression should have been measured with more than one tool. In our study, 54,2% of participants experienced moderate to severe depression based on the BDI-II, and the majority were from the late diagnosis group.

In our study, those in the late diagnosis group showed lower scores of the quality of life in physical health, psychological health, and social relationship domains; whereas there was no difference in the environmental domain between the late and non-late diagnosis groups. The lowest score of quality of life in the late diagnosis group in the physical domain was physical pain, in the psychological domain was negative feeling, and in the social relationship domain was support from family and friends. Based on the Spearman rank correlation test, our study also revealed a significant negative correlation between the total score of depression and domain 1 (physical health) of QoL ($p = 0.013$), domain 3 (social relationship) of QoL ($p < 0.001$), and domain 4 (environment) of QoL ($p = 0.016$). QoL is a fundamental component of the well-being of PLWHA. The improvement of the QoL of PLWHA is part of the global agenda. Previous studies reported that being ART naïve, having low ART adherence, having an advanced stage of HIV, drug use, unemployment, depression, and stigma were associated with low QoL (Popping et al., 2021; Seguiti et al., 2022).

The Indonesian government launched a recommendation that the key populations visit healthcare facilities at least every three months or monthly for the best results.

However, most key populations had never or rarely visited healthcare facilities, which made them difficult to reach and delayed the provision of the HIV care continuum. Before 2017, PLWHA in Indonesia received ART initiation from a hospital when their CD4 cell count was less than 350 cells/mm³. Fortunately, since 2017, the policy has changed: ART initiation should begin for individuals with HIV positive regardless of their CD4 cell counts, and ART could be given at Puskesmas, a primary healthcare service at the subdistrict level (Ministry of Health of the Republic of Indonesia, 2017).

HIV prevention and control programs in Indonesia face numerous challenges. There were gaps in new HIV case detection, maintaining treatment, viral load testing, and infrastructure for people living with HIV/AIDS (PLWHA) in terms of logistics of medicines and health supplies, quantity and capacity of human resources for program services; modalities of preventing HIV and STI transmission in key population; and financing key population outreach that is dependent on international partners. Despite the five-year 2020-2024 national action plan for preventing and controlling HIV/AIDS and STIs, Indonesia was still far from the target achievement (Ministry of Health of the Republic of Indonesia, 2022).

To prevent HIV-late diagnosis, primary healthcare institutions should cooperate with HIV-related NGOs to actively engage in mobile VCT at hotels, massage parlors, bars, and other high-risk places for sexual transactions. All PLWHA should receive dynamic stages of HIV care from linkage to care, retention in care, adherence to ART, and viral suppression. The elimination of stigma and discrimination, the involvement of interprofessional collaborative practice, community

engagement, and medical-legal partnership are needed to achieve health equity and better health outcomes for PLWHA (UNAIDS, 2022; Lippman et al., 2022).

Lastly, our study had some strengths and limitations. The strength of our study was shown in the mixed-method design and multidimensional assessment, which offered a holistic view of factors associated with late HIV diagnosis. This study specifically targeted key and vulnerable populations in Surabaya, providing valuable insight into a group often underrepresented in health research. Further, the inclusion of NGO staff perspectives highlighted the important role of community-based organizations and enhanced the relevance and applicability of the findings for public health interventions. The limitations of our study were related to the use of a cross-sectional design, which does not allow for causal inferences of changes over time in behavior or mental health; and as the study was conducted in a small sample size in a single city, findings might not be generalizable to broader populations; which should be addressed in a similar study in the future (Shorten & Smith, 2017).

Conclusion

This study highlights critical barriers to early HIV diagnosis and sustained care among key and vulnerable populations in Surabaya, Indonesia. Over half of the participants were diagnosed late, and this group exhibited significantly poorer physical and psychological health, lower cognitive function, and greater levels of depression. Key contributing factors included limited HIV knowledge, stigma, and concealment of HIV status from families. The findings underscore the essential role of NGOs in bridging gaps in education, support, and access to health services. Strengthening

community-based interventions, enhancing mental health support, and addressing stigma are vital to improving HIV outcomes in these populations.

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Conflict of interest

None to declare.

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