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Impact of COVID-19 Among HIV Key Population as Informal Workers

Caroline Thomas[1], Catherine Thomas[1,2], Claudius Novchovick Mone Iye[1]

[1] Yayasan Peduli Hati Bangsa, Jakarta, Indonesia
[2] Universitas Katolik Indonesia Atma Jaya, Jakarta, Indonesia

Corresponding address: Caroline Thomas
Email: peduli.hati.indonesia@gmail.com

Abstract

Background: HIV cases are still increasing in Indonesia. With the spread of COVID-19, HIV key populations are experiencing undesirable outcomes in social, financial, access to health and food resources. The study aimed to assess the impact of COVID-19 among key populations & PLHIV in Indonesia.
Method: Yayasan Peduli Hati Bangsa conducted a participatory research in October to December 2020 to capture and assess the impact of Covid-19, combining and adapting the formats of a 'Citizen's report card', a 'Community assessment', and a qualitative survey.
Results: Out of 15 participants who were PLHIV and key populations, mostly perceived that COVID-19 had impacted them financially, especially for those who work in informal sectors. Food assistance from the Government was provided at least once a month and the nutritional value was perceived as substandard. Having said that, participants did not consider the nutrition as crucial, as long as they had something to eat. Most of the participants observed that mental health issues were related to their physical health and financial adequacy. Additionally, sources of anxiety arose from the uncertainty in financial income. Lastly, the government was perceived as overly prioritizing COVID-19 while neglecting other health services.
Conclusion: Participants in this study wished that government would improve the healthcare and assistance programs for the vulnerable ones affected by COVID-19. Equal and well-targeted distribution of assistance, as well as provision of access to jobs, were the ones that need to be majorly improved by the government.
Keywords: HIV, Impact of COVID-19, informal workers

Abstrak

Latar belakang: *Kasus HIV di Indonesia masih terus meningkat. Dengan penyebaran COVID-19, banyak populasi mengalami hasil yang tidak diinginkan di bidang sosial, keuangan, serta akses pada layanan kesehatan dan sumber makanan. Kajian ini khusus menilai dampak COVID-19 pada populasi kunci & ODHA di Indonesia.*
Metode: *Yayasan Peduli Hati Bangsa melakukan penelitian partisipatif pada Oktober sampai Desember 2020 untuk mendapatkan informasi dan menilai dampak Covid-19, menggabungkan dan mengadaptasi format 'Laporan Warga', 'Penilaian Komunitas', dan survei kualitatif.*
Hasil: *Dari 15 peserta yang merupakan orang dengan HIV dan populasi kunci, sebagian besar merasa bahwa COVID-19 berdampak pada mereka secara finansial, terutama bagi mereka yang bekerja di sektor informal. Bantuan pangan dari Pemerintah diberikan minimal sebulan sekali dan nilai gizinya dinilai masih di bawah standar. Meski demikian, peserta tidak menganggap nutrisi sebagai hal yang penting, selama mereka memiliki sesuatu untuk dimakan. Sebagian besar peserta mengamati bahwa masalah kesehatan mental terkait dengan kesehatan fisik dan kecukupan keuangan mereka. Selain itu, sumber kecemasan muncul dari ketidakpastian pendapatan finansial. Peserta juga merasa bahwa pemerintah dianggap terlalu memprioritaskan COVID-19 dengan mengabaikan layanan kesehatan lainnya.*
Simpulan: *Peserta dalam penelitian ini berharap agar pemerintah meningkatkan program kesehatan dan bantuan bagi mereka yang rentan terdampak COVID-19. Penyaluran bantuan yang merata dan tepat sasaran, serta penyediaan akses lapangan kerja, menurut para peserta merupakan hal yang harus ditingkatkan secara besar-besaran oleh pemerintah.*
Kata kunci: *HIV, dampak COVID-19, pekerja informal*

Introduction

At the present day, the novel coronavirus has infected more than 4,5 million people and causing death of approximately 145 thousand patients in all 34 provinces in Indonesia. With the indiscriminating spread of COVID-19, many groups of populations are experiencing undesirable impact in terms of social, financial, health and food securities. Some of the most disadvantaged in the COVID-19 era are people living with HIV/AIDS and vulnerable key populations.

In Indonesia, new infections of HIV have risen from 7,000 annually in 2006 to 48,000 annually in 2017. Despite of the rising number, the number of newly diagnosed cases had dropped to 9,000 in 2017 from previously over 12,000 in 2013. Women accounted over 35% of new infections annually in Indonesia. More than 50% of HIV diagnoses are made when patients are in the late stage. In addition, stigma and discrimination are still strong obstacles in prevention and treatment but also there are considerable challenges in access to appropriate anti-retroviral therapy.[2]

As of December 2019, data shows that the cumulative number of reported HIV cases was 377,564 (65.6% of the 2016 estimated 90% target of PLHIV).[3] Not all of those diagnosed with HIV have received ARVs and only 47% are still receiving ARVs routinely. The lost to follow up rate for ARV treatment is approximately 21%.[4]

Changes during the COVID-19 pandemic may have impacted HIV patients and key populations in Indonesia in variety of ways. The study, therefore, was aimed to assess the impact of COVID-19 on health access among key populations & PLHIV in Indonesia.

Methods

Site

Indonesia is a country in Southeast Asia. It consists of 34 provinces in 5 major islands, including Java, Sumatra, Kalimantan, Sulawesi, and Papua. Data collection was done face-to-face with 14 community assessors from Jakarta and 1 from Bekasi (West Java) which is located in the outskirt of Jakarta.

Populations

The study was done to assess the impact of COVID-19 on health access among key populations & PLHIV in Indonesia.

Participants of this study are community members which will be referred to as Assessor. Assessor populations in this study may not be from a single population, but rather a multiple population of either one or more than one of:

- **PLHIV** or in local terms referred to ODHA, in short for *Orang yang Hidup dengan HIV AIDS*, defined as people who are infected with HIV.
- **PWID** or in local terms referred to Penasun, in short for *Pengguna Napza Suntik*. WHO defined PWID as "*people who inject psychotropic (or psychoactive) substances for non-medical purposes. These drugs include, but are not limited to, opioids, amphetamine-type stimulants, cocaine, hypno-sedatives and hallucinogens. Injection may be through intravenous, intramuscular, subcutaneous or other injectable routes. People who self-inject medicines for medical purposes – referred to as "therapeutic injection" – are not included in this definition. The definition also does not include individuals who self-inject non-psychotropic substances, such as steroids or other hormones, for body shaping or improving athletic performance*".[5]
- **Sex workers** include female, male and transgender adults (18 years of age and above) who receive money or goods in exchange for sexual services, either regularly or occasionally. Sex work is consensual sex between adults, can take many forms, and varies between and within countries and communities. Sex work also varies in the degree to which it is more or less "formal", or organized.[6]
- **Transgender** is an umbrella term for people whose gender identity and expression does not conform to the norms and expectations traditionally associated with the sex assigned to them at birth; it includes people who are transsexual, transgender or otherwise gender non-conforming.[7, 8] Transgender people may self-identify as transgender, female, male, transwoman or transman, trans-sexual or, in specific cultures, as *hijra* (India), *kathoey* (Tha iland), *waria* (Indonesia) or one of many other

transgender identities. They may express their genders in a variety of masculine, feminine and/or androgynous ways. The high vulnerability and specific health needs of transgender people necessitates a distinct and independent status in the global HIV response.

– **Men who have sex with men** refers to all men who engage in sexual and/or romantic relations with other men. The words "men" and "sex" are interpreted differently in diverse cultures and societies and by the individuals involved. Therefore, the term encompasses the large variety of settings and contexts in which male-to-male sex takes place, regardless of multiple motivations for engaging in sex, self-determined sexual and gender identities, and various identifications with any particular community or social group.[9]

Selection of Community Assessors

Recruitment of assessors include the use of purposive and snowball sampling methods. Participants were selected from the internal list of contacts of the collaborating organization. After a list of selected prospective participants was created, approaches were made via phone, and social media applications based on the availability of the contact information. Invitation to participate in the assessment was done by sharing the information sheet and formal invitation through WhatsApp application and email, and by orally explaining the purpose of the assessment. Consent was given both through written on the first page of the assessment form.

Assessment Tool

A participatory research tool was developed collaboratively by Peduli Hati Bangsa and ITPC to capture and assess the impacts of Covid-19, combining and adapting the formats of a 'Citizen's report card', a 'Community assessment', and a qualitative survey.[10] The tool used images and emoticons to encourage participants, regardless of literacy, to relate their experiences of healthcare services as people living with HIV, and to rank their government's actions on health provisions and human rights both prior to and during the Covid-19 pandemic. Every component of the tool's development and implementation was collaborative, from the formulation of indicators, to its inclusive design and analysis of findings.

The tool included nine indicators:

1. HIV testing
2. Antiretroviral treatment (including ARV for children)
3. HIV related services (harm reduction, maternal and child health, STI)
4. Employment and income
5. Food security
6. Safe place to live
7. Violence, stigma, discrimination
8. Mental health (anxiety/depression, etc)
9. Public trust to Government

While structured according to these indicators, narrative response fields were blank, encouraging participants to relate whatever they determined to be relevant and meaningful. Two response fields for each indicator elicited information about users' experiences both prior to and during the Covid-19 pandemic. The last section of the tool encouraged users to convey strengths and weaknesses in the public health and social support systems, and to articulate their needs for health and social services now and in the future.

Data Collection

Data collection were done face-to-face in 2 groups (morning and afternoon) to allow social distancing in the room. Morning session was done with 8 participants from 10 am to 12 noon and afternoon session was done with 7 participants from 2 to 4 in the afternoon. There were no non-participants present during the sessions.

Data analysis

Result of the data were transferred into an Excel sheet template. To ease the analysis process, the template also includes demographic data voluntarily provided by the informants (i.e., pseudonym, gender, age, education, profession, risk factor, marital status, and area of residence). No personal identifier (real name, addresses, phone numbers) were included in the template as each participant had an assigned label (by number). Level of analysis were done question by question and by indicators.

Results

The sociodemographic profile of the participants is presented below.

HIV testing

Most of the participants agreed that prior to COVID-19 pandemic, HIV testing was easy and education about HIV testing was routinely done among key population. There were still frequent HIV tests at the *Puskesmas* (Public Health Center) or mobile clinic and there was no limitation in the working days of services. Hours of service ranges from 7 in the morning up to 4 in the afternoon, and doctors were not in a hurry to examine the patient. In addition, doctors also did not keep a distance with the patients. Only one female participant perceived that the doctor in the HIV testing services were not friendly and snob. In terms of the services, HIV testing services were considered simple and affordable. Particular to the transgender participants, the group considered coming to routine HIV testing pre-COVID-19 as a venue to socialize.

After COVID-19, however, routine tests among all population were not done (either through mobile or facility based). Number of people accessing HIV test were decreasing. When HIV test result is available, healthcare provider was perceived by participants to be in a hurry and did not explain the result or educate the patients. Apart from that, participants also brought up the issue of service hours that have become limited during the pandemic. Participants reported that the services hours only ranged from 8 in the morning to 1 in the afternoon, and it is only offered on 2 working days per week. Some of the transgender participants who also work as NGO field worker also stated that they can only bring a maximum of 2 persons per day to be tested, and everything had to be done by appointment.

Table 1. Sociodemographic Profile of Participants Study Sites (n=15)

Demographic Data	Gender		
	Male (n=4)	Female (n=5)	Transgender (n=6)
Average age	38.5	36.4	51.1
Level of Education			
Elementary	0 (0%)	0 (0%)	3 (50%)
Middle School	0 (0%)	1 (20%)	1 (16.7%)
High School	3 (75%)	2 (40%)	2 (33.3%)
Undergraduate	1 (25%)	2 (40%)	0 (0%)
Post-graduate	0 (0%)	0 (0%)	0 (0%)
Region			
Java	4 (100%)	5 (100%)	6 (100%)
Marital Status			
Single	0 (0%)	1 (20%)	4 (66.7%)
Married	4 (100%)	3 (60%)	0 (0%)
Divorced	0 (0%)	0 (0%)	0 (0%)
Widowed	0 (0%)	1 (20%)	0 (0%)
In a relationship, cohabiting	0 (0%)	0 (0%)	2 (33.3%)
In a relationship, not cohabiting	0 (0%)	0 (0%)	0 (0%)

Occupation			
Salesman and motorbike online driver	1 (25%)	0 (0%)	0 (0%)
Housewife	0 (0%)	2 (40%)	0 (0%)
Entrepreneur	1 (25%)	1 (20%)	0 (0%)
Gymnastic coach	0 (0%)	1 (20%)	0 (0%)
Unemployed	1 (25%)	0 0%)	0 (0%)
Parking attendants and motorbike online driver	0 (0%)	1 (20%)	0 (0%)
Courier	1 (25%)	0 (0%)	0 (0%)
Sex worker	0 (0%)	0 (0%)	1 (16.7%)
NGO field worker and sex worker	0 (0%)	0 (0%)	2 (33.3%)
Salon owner	0 (0%)	0 (0%)	3 (50%)
Risk factor			
PWID	3 (75%)	5 (100%)	0 (0%)
Partner of transgender/ MSM	1 (25)	0 (0%)	0 (0%)
Transgender	0 (0%)	0 (0%)	6 (100%)

Antiretroviral treatment

Before COVID-19, most of the participants stated that the ARV stock was safe. ARV access was considered as easy, simple, comfortable, and uncomplicated. Some doctors also offered to open the services on Saturday, Sunday, or holiday to help patients accessing ARVs. Similar to HIV testing, transgender participants also considered coming to ARV center as a venue to socialize with other PLHIV.

During Covid-19, the service hours were reduced from 8 in the morning to 12 noon. ARV counseling and drug prescription refill were not well-flowed. The drug stock is barely sufficient to meet the patients' demands. One male participant mentioned that once he was only given ARV for 2 weeks because of the shortage of stock. Only one female participant specified that the multi-month dispensing was allowed.

On the doctors' services, a female participant thought that it was a pity that the doctors do not have time to speak to the patients, as doctors' appointment only lasts for 5 minutes. In addition, participants also reported that doctors keep physical distance with their patients, and therefore physical examination health services for PLHIV were limited. Patients were also required to request an appointment by phone. In terms of the cost, one male participant stated that during COVID-19, PLHIV does not have to pay for ARV and registration fee.

HIV related services (harm reduction, maternal and child health, STI)

Most of male and female participants were PWID who access harm reduction services. Only one male who is a partner of transgender who are accessing routine STI services. All transgender participants were accessing routine STI services. Before COVID-19, healthcare providers in all HIV-related services were perceived to

have more time to educate the patients. Methadone users stated that they can still discuss with the doctors to adjust the dosage, and methadone can be accessed daily from 8 in the morning to 12 noon and service providers were not deemed to be hasty in providing care.

Most of the transgender participants were accessing STI services and they feel that that the doctors and counselors were kind and were friendly to them. Similar to HIV testing and ARV, going to STI services were also considered as a chance to make new friends according to this group. All transgender assessors considered the STI services satisfactory.

During COVID-19, one Suboxone user said that the price of IDR 80,000 ($5.5) for 8mg per day became too expensive because his income was not as much as before COVID-19.

Specifically for methadone user, tapering down the methadone dosage were not allowed, and methadone service only lasts from 8 to 10 in the morning. This is extremely difficult for female methadone user who is a single parent because she must attend to her children's needs of online study in the morning.

Most of the participants affirmed that the information and education were not performed because healthcare providers were afraid to be infected with COVID-19 even though they were wearing PPE. Rapid tests or swab tests were not offered to the patients either. Additionally, procedures to enter hospitals or clinics were considered as complicated because they have to make appointments, apply social distancing, wear masks, and wash their hands. Apart from the procedures, they were also concerned about the risk of getting infected with COVID-19.

Employment and income

Prior to COVID-19, all participants considered their income as sufficient or adequate to fulfil family or individual needs and save money. Some people were able to make ends meet by working double job since there were no restrictions in travelling. Specifically for transgender assessors, if they are working as NGO staff in the morning, they were still able to work as sex workers in the evening to get additional income. Most of the working male participants occupation requires travelling because they were either a courier/delivery man, salesman, or motorbike online driver. During COVID-19, however, most of the participants agreed that their income was greatly reduced. Some participants even mentioned that in some months, their income was zero.

Most of the male participants worked as food or goods delivery man prior to COVID-19. Since the lockdown, all malls or the food producers were closed, therefore their income was reduced. Some were even laid off during COVID-19 pandemic.

One male participant who works night shift as motorbike drivers to transgender sex worker stated that since the lockdown, sex workers were not allowed to travel or bring customers to their place. Therefore, his income was also impacted.

As for female participants who were housewives, their income were dependent to their husband or partners. Two housewives and two NGO workers were also working voluntarily as field worker, which usually be compensated for their time by being provided with transport fee. However, since COVID-19, the number of visits to the hospital is limited, and therefore their income is also reduced.

Transgender assessors who are working at a hair salon stated that people are afraid to come to the salon during COVID-19. Some also added that they have to live with their family since they could not afford to even pay for the electricity bill.

Food security

Most of the participants said that prior to COVID-19, their income was sufficient to buy groceries and daily food items. Some participants said they were still able to save because they worked full time. Income was considered stable and they can still eat 3 times a day.

During COVID-19, most of the participants received food assistance from the Government at least once a month. Most of the Government supply includes rice, instant noodle or canned sardines. One male participant, however, mentioned that the prices of food are increased are food supplies are limited. Most of the participants must save food as much as possible to be able to eat. One female participant who is a parking attendant said that sometimes she was not able to meet 3 meals a day. Most of the participants who are struggling with food security mentioned that they are eating only to "fill their tummy", and taking nutritious food intake was not considered crucial as long as they are eating.

Safe place to live

Most of the participants lived in rented houses and felt comfortable and proper even though they had to live in a slightly densely populated area. Participants did not only associate safe place to live with having a physical house but also the ability to socialize with relatives or neighbors.

During lockdown, participants mentioned that many roads were blocked, and curfews were implemented. Therefore, the ability to socialize with relatives or neighbors were also limited. One participant who lived with a housemate said that her house mate was working as a cleaning lady and consequently she had to go to work and exposed her to COVID-19. One female participant who lived in temporary housing feel that the situation around her place became less secure because there were many unemployed people and many incidents of theft.

Violence, stigma, discrimination

Most of the participant did not perceive being stigmatized or discriminated prior to COVID-19 associated with the HIV status or being a PWID. One male participant, however, mentioned that he had experienced discrimination when accessing services (injury due to accident). Upon disclosing his HIV status, medical personnel immediately took a step back when they were about to take medical action. The staff's reaction made him uncomfortable. Some were also outcasted from the family because of the HIV status. One family was able to accept the participant after an explanation from the doctor. Some participants had not disclosed their HIV status to their family members. Particular to transgender group, participants stated that they were not discriminated or stigmatized due to their HIV status, but people were rather nosy and insulting due to their physical appearance.

One female participant mentioned that discrimination and stigma against her remains the same as before the pandemic. She was judged by her own family members due to her PWID status. If something was missing around the house, she would be accused because of her background as drug user.

During COVID-19, participants mentioned that in addition to the experience of stigma and discrimination prior to COVID-19, some healthcare providers did not want to serve patients, did not want to be physically meet patients, or literally expressed disgusted.

Two female participants and one transgender participant expressed that violence increased in their neighborhood because many people had been laid off due to the pandemic.

Mental health (anxiety/depression, etc)

Most of the participants observed mental health are related to physical health and financial adequacy. Prior to COVID-19, participants were able to play with the kids, and spend quality time with family. Mostly agreed that there was no feeling of pressure or fear, and that their life was full of peace. During the pandemic, two female participants experienced loss. One experienced the loss of a daughter and mother consecutively within few months, and one experienced the loss of her husband.

One male participant who access mental health services stated that there is still a lack of free mental health services. Good services are only obtained at paid doctor's offices, which can be quite expensive. Many worries arose from the financial uncertainty during the pandemic.

Apart from financial problems, stress and depression were also boredom, confusion, feeling anxious of staying at home but at the same time, participant felt discomfort to go out from the house because of the fear of being exposed to COVID-19. One transgender participant felt restless and agitated since she wanted to return to their hometown, but she had not disclosed her HIV status to her family member.

Public trust on Government

Most participants expressed positive statements towards the Government prior to COVID-19, that for the current regional development has started to be evenly distributed from cities to villages. Those who expressed negative statements towards the Government mainly pointed out the distrust in terms of policy (one male participant expressed that the policy is only benefit to the affluent but not to the disadvantaged people) and corruption.

Trust on Government during COVID-19 pandemic is mostly related to food assistance, either in the distribution system or the number of goods

distributed. If a participant is receiving assistance from the Government, they would be more likely to trust the Government.

One female participant mentioned that during pandemic, she became increasingly distrustful to the Government. In her opinion, COVID-19 is used as a business field for the Government. Rapid test, for example, can be as overpriced as Rp. 600,000 ($41) while the actual price test kits is only Rp. 150,000 ($10). The government is also perceived to overly prioritizing COVID-19 while neglecting other health services.

Discussion

COVID-19 had impacted not only health but also other aspects in life of a person living with HIV. While HIV related access has become limited in terms of service hours as well as quality, COVID-19 had also impacted other qualities in a life of the participants. COVID-19 undoubtedly affected employment and income of the participants which may directly influenced one's decision to access healthcare. The financial inadequacy may play a major role in the mental health. However, fear, loss, boredom, confusion and anxiety are also mentioned by the participants. Other than access to antiretroviral treatment and HIV related services, for a person living with HIV to improve the overall quality of life, sufficient nutrients is required to maintain or promote stronger immune system. During COVID-19, most of the participants are struggling with adequate nutritious food intake. With prolonged situation, without any steps taken to mitigate this issue, poor nutrition may increase the susceptibility to infections, and infections intensify poor nutrition.

These results may be interpreted with caution, while there are only 15 participants in this study, one of the major donors for HIV, The Global Fund, reported in their 2021 Impact Results Report shows that while some progress was made, key programmatic results have declined for the first time in the history due to COVID-19.[11] This report also highlights significant declines in HIV testing and prevention services for key and vulnerable populations who were already disproportionately affected.

Conclusion

Participants in this study are affected by COVID-19 not only in terms of health access related to HIV diagnosis and treatment as well as other related services such as harm reduction and STI services. COVID-19 had also impacted employment and income of people living with HIV which eventually impacted food security and access to adequate nutritious food. Most of the participants also observed mental health are related to physical health and financial adequacy. Participants wished that government would improve the healthcare and assistance programs for the vulnerable ones affected by COVID-19. Equal and well targeted distribution of assistance, as well as provision of access to jobs, according to the participants were the ones to be majorly improved by the government.

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Conflicts of interest

Authors had no conflict of interest.

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