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Lived experience, social support, and challenges to health service use during the COVID-19 pandemic among HIV key populations in Indonesia

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Abstract

The COVID-19 pandemic has greatly affected the lives, health, and social well-being of people globally including presenting special challenges in low to middle income countries for people living with HIV. This study investigates the pandemic experiences of the four key HIV-positive populations in Indonesia: men who have sex with men, transgender women, female sex workers, and people who use drugs. In-depth interviews were conducted with a convenience sample of 22 key population members recruited through 9 nongovernment HIV agencies in Jakarta and Bali, Indonesia. Indonesia's Large-scale Social Restrictions Policy mandating physical distancing and stay-at-home orders had been in effect for 7–10 months at the time of the interviews. The interviews were audio-recorded, transcribed, and coded using NVivo™ (R1.7) software. A grounded theory approach identified key concepts along with similarities, differences, and reoccurring patterns of COVID-19 lived experience among participants. Participants recounted the impact of both the pandemic and the Restriction Policy on their interpersonal, financial, medical, and psychosocial well-being. When in need, they turned to formal and informal sources of financial and social support plus their own resourcefulness. Along with other factors, HIV medication shortages, HIV and COVID-19 related stigma, and fear of acquiring COVID-19 negatively impacted their antiretroviral adherence and the use of health services. The results point to the latent consequences of government attempts to curb a pandemic through public health lockdowns and enforced policies of physical separation. Its findings reveal the importance of ensuring that public safety nets for HIV key populations are available to supplement more informal personal sources of needed support.

Keywords COVID-19 Indonesia, HIV key populations, Effects of government COVID-19 policy, Social support, Health services experience, Antiretroviral adherence

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Introduction

The COVID-19 pandemic has greatly disrupted many aspects of human life throughout the world while exerting a severe effect on the social fabric, economy, and population health of many countries. The governmental policies enacted as a result of the pandemic were in some cases draconian. Mounting mortality and morbidity rates of COVID-19 led multiple governments to enact large-scale restrictions on population mobility, group and mass gatherings, and face-to-face social and physical interaction. Legal mandates to observe physical distancing between individuals significantly altered “normal” human routines and redefined the nature of interpersonal relationships [1, 2].

Numerous studies have investigated the pandemic's effects on the health and well-being of people who are HIV-positive [3]. Results show that the many structural, cultural, psychosocial, and health factors that surround and complicate the lives of people living with HIV (PLWH) have both produced and exacerbated the challenges of living within the psychosocial and physical environment imposed by the pandemic. Yet despite a growing body of global research in multiple countries around the globe, few studies appear to specifically examine the combined effect of HIV and COVID-19 on the life experiences and psychosocial well-being of PLWH in Southeast Asia. The few exceptions include research investigating personal access to health care and supportive services in Malaysia among PLWH who use drugs [4], HIV disclosure dilemmas among HIV-positive women seeking COVID-19 treatment in Sumatra, Indonesia [5], and COVID-related threats to health and well-being among vulnerable HIV groups in Vietnam [1].

Drawing on data collected through qualitative in-depth interviews, this paper addresses this existing gap in HIV science by examining the impact of the pandemic on the lived experience, social support, and challenges to health service use among members of four HIV key populations in Indonesia during the first year of the country's COVID-19 pandemic. Home to the world's fourth largest population, Indonesia has experienced one of the highest rates of COVID-19 infections in the region since the start of the pandemic, and its number of COVID-19 deaths rank uppermost in Southeast Asia [6]. In addition, although Indonesia has seen a gradual reduction in annual HIV incidence since 2010, its estimated number of people dying from HIV-related medical causes has continued to rise [7, 8]. From this syndemic standpoint, Indonesia offers a highly important and informative vantage from which to study the effects of two intersecting pandemics on PLWH.

Indonesia's first case of COVID-19 was confirmed in March 2020. As of January 2023, more than 6

million people had been diagnosed with the virus and over 160,000 Indonesians had died [9]. The Indonesian government's initial response to the country's rising pandemic was to institute a Large-scale Social Restrictions Policy (*Pembatasan Sosial Berskala Besar*) in Jakarta, Bali, and several other cities and provinces with mounting COVID-19 prevalence. The policy permitted essential offices and factories to remain open but restricted the activities of nonessential firms [10]. It also allowed people to engage in religious and essential life activities within certain limitations while simultaneously mandating school closings, prohibiting most internal and international travel, reducing public transportation, and issuing stay-at-home requirements except for essential trips. As the outbreak worsened, the government implemented a subsequent series of mandates designed to further restrict community interaction and population mobility [10, 11].

Like other low-and middle-income countries (LMICs) with limited health resources [12], Indonesia has struggled throughout the COVID-19 pandemic with little available money to keep its citizens healthy or to supplement the income of those facing financial destitution due to its effects. With a chronically understaffed workforce and underfunded infrastructure, the added demands of the pandemic placed an additional burden on Indonesia's already vulnerable health care system and strained its pre-COVID-19 delivery of HIV medical services and treatment for PLWH [13].

It is within this highly challenged socio-economic context that this study investigates the COVID-19 related experiences of the four major HIV-positive key populations in Indonesia: men who have sex with men (MSM), transgender women (TGW), female sex workers (FSW), and people who use drugs (PWUD). In examining their experiences, the study helps to extend the slim body of non-clinical research that considers the dual effects of COVID-19 and HIV on PLWH in a South-East Asian country. The study's inductive qualitative approach allows study participants to describe their experiences in their own way and in their own words. Their accounts provide insight into the latent consequences for PLWH of government attempts to curb infectious disease transmission through large-scale community lockdowns and social distancing mandates. Embedded in the participants' words and experiences are clues as to social policy and intervention strategies that may be needed to assist PLWH as the COVID-19 pandemic recedes globally, but its negative psychosocial and economic residual effects continue in Indonesia and likely in other LMICs as new pandemics possibly emerge to take its place. Also, the study's results are highly informative within both a pandemic and non-pandemic context in enabling stakeholders across various

sectors to more fully comprehend and effectively prepare for future public health challenges. In addition, the participants' experiences are vivid reminders of the importance of ensuring that public safety nets for PLWH are available if needed that supplement and assist more informal sources of instrumental and psychosocial support provided by family, friends, and others in the community.

Methods

The data were collected in October through December 2020 when Indonesia's Large-scale Social Restrictions Policy had been in effect for approximately 7–10 months. Twenty-two participants were recruited for in-depth interviewing, at which time theoretical saturation was reached and nothing new was being learned. Members of all four Indonesia's HIV key population (FSW, MSM, TGW, and PWUD) were included to assure their representation. Recruitment, including participants for in-depth interviewing, was conducted in Jakarta and Bali, Indonesia through referral from 9 nongovernment (NGO) agencies and other local community groups that specifically serve PLWH. The participating NGOs and local agencies posted information on their social media accounts about the study and its request for potential participants. Individuals who thought that they might qualify and were interested in possibly participating were told to contact the study's research team to learn more about the study and for eligibility screening. To be eligible to participate in the study, participants had to be HIV-positive, a member of a key population (FSW, MSM, TGW, or PWUD), receiving ARV treatment, and willing to provide informed consent to be interviewed and audio-recorded.

The in-depth interviews were conducted in Bahasa Indonesian by trained, native-speaking interviewers. Based on relevant theory, key issues, and findings in the HIV and COVID-19 literature, the research team developed a qualitative interview guide designed to explore the impact of COVID-19 pandemic on the participants' life (work and routines, social relationships, physical being such as medication and mental health), social support, and access to health services (see Appendix 1). Participants could select which of three interviewing methods that they preferred: by Zoom (either with video or audio only), WhatsApp (either with video or audio only), or telephone (audio only). While these various options can elicit differing volumes of data, the thematic content that they produce is the same [14]. Interview questions asked participants about their interpersonal, psychosocial, and practical experiences with COVID-19 during the government COVID-19 lock-down. The audio-taped interviews lasted from 50 to 120 min. The analytic criterion of "saturation" [17] was met with 22 interviews, at

which time data collection ceased as no new themes, categories, or insights continued to emerge from the data. Participants received 200,000 Indonesian Rupiah (about \$13 USD) as compensation for their time and internet or phone costs. The study was approved for research conduct by the Human Research Ethics Committee of the Faculty of Medicine, Udayana University/Sanglah Hospital with ethical clearance number 1806/UN14.2.2.VII.14/LT/2020. Informed consent was obtained from all individual participants included in the study.

Data coding and analysis

The audio-recorded interviews were transcribed verbatim and coded using NVivo™ software version R1.7. Consistent with a lived experience perspective, the participants' accounts formed the unit of analysis. The data were conceptually analyzed using grounded theory, an approach to developing theories and deriving insights about often little-known phenomena through the inductive analysis of data collected directly from research participants [15]. In this study, it was used to identify key concepts along with their possible relationships to each other and to explore similarities, differences, and reoccurring COVID-19 experiences among and between participants. The coding process began by reading and rereading all interview transcripts to identify patterns and themes in the data related to the participants' COVID-19 experiences. Second level coding involved identifying clusters of experiences and patterns of behavior that fit under each of these three coding categories. These subcategories were checked against each other to identify both consensus and diversity among participants in their COVID-19 accounts.

Results

Table 1 reports the demographic characteristic of participants categorized according to how they self-identified when seeking HIV services from one of the study's seven referring organizations. Of the 22 participants, 9 (41%) self-identified as MSM, 5 (23%) as FSW, 4 (18%) as TGW, and 4 (18%) as PWUD. Most participants (59%) were between 29 to 39 years of age. Females, including 4 transwomen, made up nearly 41% of the sample. Of the 22 participants, only 4 (18%) were unemployed with the remainder working either as staff at an NGO, within the private sector, as small business entrepreneurs, or as commercial sex workers. Sixteen (70%) had attended or graduated from senior high school including 4 participants who had attended college. MSM reported the highest level of educational attainment of all four key population groups. Slightly more participants were from Jakarta (53%) than Bali. Three major experiential categories emerged out of the data: the impact of the pandemic

Table 1 Demographic characteristics of participants by key population (N=22)

Variable	MSM (n = 9) n (%)	FSW (n = 5) n (%)	TGW (n = 4) n (%)	PWUD (n = 4) n (%)	Total n (%)
Age in years					
18–28	1 (4.5)		1 (4.5)		2 (9.1)
29–39	6 (27.3)	4 (18.2)	3 (13.6)	4 (18.2)	17 (77.3)
> 40	2 (9.1)	1 (4.5)			3 (13.6)
Gender					
Male	9 (40.9)			4 (18.2)	13 (59.1)
Female		5 (22.7)			9 (40.9)
Transgender woman			4 (18.2)		
Educational Background					
Elementary School	1 (4.5)		1 (4.5)		2 (9.1)
Junior High School		2 (9.1)	2 (9.1)		4 (18.2)
Senior High School	4 (18.2)	3 (13.6)	1 (4.5)	4 (18.2)	12 (52.5)
Undergraduate	4 (18.2)				4 (18.2)
Occupation					
NGOs related to HIV	4 (18.2)	1 (4.5)	1 (4.5)	1 (4.5)	7 (31.8)
Private sector	3 (13.6)			1 (4.5)	4 (18.2)
Self-employed	1 (4.5)	4 (18.2)	2 (9.1)		7 (31.8)
Unemployed	1 (4.5)		1 (4.5)	2 (9.1)	4 (18.2)
Residency					
Jakarta (and suburban area)	4 (18.2)	2 (9.1)	2 (9.1)	4 (18.2)	12 (52.5)
Bali	5 (22.7)	3 (13.6)	2 (9.1)		10 (45.5)

MSM Men Sex with Men, FSW Female Sex Worker, TGW Transgender Woman, PWUD People Who Use Illicit Drugs

and government lock-down policies on participants' interpersonal, financial, medical, and psychosocial well-being; formal and informal sources of social support; and challenges related to health service use.

Impact of the pandemic on the lived experience of Indonesia's HIV key populations

Impact on financial security

All 22 respondents reported being under considerable financial stress due to a range of COVID-19-related income challenges that included potential or actual job loss, reduced working hours, loss of employment-related benefits, and/or job insecurity. A transgender woman explains about the financial challenges of becoming destitute due to COVID-19:

Since COVID-19, I lost one job, and my daily income decreased, not increased. In fact, I have nothing at all. There is no income, yet the rent has to be paid, the electricity has to be paid, the water has to be paid. (01, TGW, Jakarta)

Working strictly from home during the lock-down could offer participants working for agencies, schools, and small business firms the opportunity through the

internet for continued employment, but not without income loss. NGO personnel, for example, complained of losing transportation and food allowances that were customary job entitlements. Pre-COVID-19, they had received monetary compensation above their basic salaries to cover meals, public transportation costs, and other expenses incurred when working in the community. Such compensation could be stretched to help offset minor nonemployment-related personal expenses. Now under COVID-19, they were solely reimbursed for home internet fees incurred when attending staff meetings or conducting community outreach work via zoom:

In terms of [income from] work, it has decreased because we received additional compensation for food and transportation for doing community outreach. When we are WFH (working from home), we do not have that compensation anymore and instead receive only small amounts for zoom meetings and for all kinds of online activities. So my salary has been much reduced to almost half of what it was before. (08, TGW, Jakarta)

Meanwhile, participants who engaged in commercial sex reported shrinking income as client demand

diminished. The government lockdown, the rigors of maintaining physical distancing, and worry about acquiring COVID-19 discouraged or negatively redefined the prevalence and nature of sex-for-money exchanges. Nonetheless, the need to support themselves and/or their families could override initial hesitation to engage in commercial sex:

I didn't lose my job. It's just that there are not as many guests as before. Sometimes there are guests, sometimes only one guest every two days. (07, FSW, Bali)

To be honest, the hardest thing was that most people wanted to have sex with me for free. Oh my gosh [I thought], I just need to eat while you want it for free. (01, TGW, Jakarta)

Other survival strategies included reducing daily meal consumption or engaging in small business ventures:

Because I was laid off my expenses increased, and my income decreased. It has been dwindling more and more. So yeah, I took an order for mending clothes and then recycling them at the cheapest prices so that I could eat. (01, TGW, Jakarta)

Impact on social relationships

All 22 participants reported that adhering to social distancing to avoid contracting COVID-19 coupled with the isolating effects of Indonesia's public health lock-down negatively affected their social relationships. Social distancing proved highly difficult to observe, especially with family members, friends, or a sexual partner. As one male participant lamented, "The toughest time during this pandemic is the limited time I have to meet with my partner. So, all this time I have just been home alone." (14, MSM, Jakarta).

Loneliness and isolation from others were frequent consequences of maintaining social distancing. So was the possibility of being resented by close family and friends for refusing to meet in person. Phone calls and online meetings could help in maintaining interpersonal contact, but these were not perceived as emotionally satisfying or socially bonding as an in-person conversation. Yet when participants did manage to get together after an extended hiatus, it was not uncommon to discover that the interpersonal quality of the relationship had deteriorated. They found that fear of contracting COVID-19 and the demands of social distancing could call into question the strength, reciprocities, and/or expectations of the relationship itself:

She was one of my best friends. Before the pandemic, I usually stayed at her house when I had to come

home late from work. One day, I asked her to let me sleepover because it was late at night, and I was scared of being mugged on the street. But she refused and said, "I'm afraid of getting COVID." It's really sad that she rejected me --- my own best friend! One day, she got COVID, and she asked me to sleepover and said that she missed me so much. I said to myself, "now, when you need me, then you allow me to sleepover." (03, FSW, Jakarta)

Impact on psychosocial and mental health

All 22 participants reported experiencing adverse psychological or mental health symptoms that they attributed to the challenges of life lived amidst a highly infectious pandemic. Psychological response to COVID-19 typically appeared in the form of fear, worry, and/or anxiety over such threats as viral exposure, dwindling personal finances, job insecurity, and uncertainty about prospects for the future:

The physical problem is that I am skinnier, but it's actually more psychological. It's harder to sleep worrying about tomorrow, worrying about getting infected with COVID. I feel that I almost have chronic depression. (17, MSM, Jakarta)

Worrying about contracting the virus with its social and physical consequences could manifest in such mental and somatic disorders as shortness of breath, headaches, eating disorders, and sleeping problems. A female sex worker from Bali complained, "My headaches have increased during the pandemic." (15, FSW, Bali). A MSM participant from Bali noted that, "What I experienced the most is insomnia." (08, MSM, Bali). Meanwhile, interpersonal disagreements and even small frustrations could evoke feelings of anger. One male participant disclosed, "I am now quicker to feel emotional and get angry. Sometimes, merely small things can be so emotional." (10, MSM, Jakarta). Yet, whom to blame for the situation was unclear as one participant mused:

Activity has decreased, work has decreased, and my income has decreased. Also, I cannot meet relatives in the village. I don't know who to be angry with. (09, MSM, Bali)

Participants discovered that working from home rather than with others or in the community could prove highly stressful due to government-imposed isolation that was often exacerbated by unreliable communication technology. A community outreach worker described the evolution from initially feeling positive about working from home to the realization that doing so could be very emotionally taxing:

Back in March, we already were working from home. [We thought initially], maybe it would be fun. "OK, we can work from home. We can arrange a work schedule." But it turns out that after 2 to 3 weeks or a month, it becomes very stressful, really stressful. We haven't met with our friends; we can't meet with our family. Everything is coordinated via zoom. With a video call, sometimes there's a lot of trouble with the signal. (07, MSM, Jakarta)

Adverse health behavior emerged or accelerated during the pandemic in what participants perceived as personal response to COVID-19-related stress and social isolation. Smoking was a common coping mechanism. Other detrimental health behavior included increased food consumption, alcohol binging, and using psychotropic or injection drugs. An individual who reported chronic substance use explained, "During this pandemic, I messed up using more amphetamine, marijuana, heroin, antidepressants." (09, PWUD, Jakarta). Another participant who regularly engaged in sex work confessed:

With the depression I've had [due to COVID], I am aware that I need to drink when I serve my clients. Then I can forget about everything, such as whether we were using a condom or not, because we were drunk. Because of my depression, I need to get drunk and smoke. I am really concerned that I will make a pattern of drinking alcohol or smoking marijuana when I serve clients." (10, MSM, Jakarta).

Impact on HIV adherence

Participants perceived their adherence to antiretroviral (ARV) therapy as consistently ranging from fair to good. In explaining why she rarely missed a dose, a sex worker explained, "I really need the medicine because I depend on my health, so I take my medication." (12, FSW, Bali). Personal experience with being hospitalized for an HIV complication or losing a close friend or partner to HIV could convince participants of the need to maintain a regular medication schedule. A woman participant recounted, "I often see bad things happening to those who don't take their ARV medication regularly or who even stop their medication. It happened to someone I knew personally." (02, TGW, Bali).

Despite best intentions, participants discovered that it could prove exceedingly difficult to maintain consistent adherence during the pandemic. Clinic hours changed for the worse to accommodate reduced staffing. Newly revised pick-up times to refill medication conflicted with many work schedules. One participant complained, "I had to stop taking ARV for three days because there really wasn't any stock at the clinic." (01, MSM, Bali).

Participants reported that clinic healthcare workers tried to ameliorate ARV shortages by rationing medication dosages while awaiting the arrival of new supplies or by referring patients to larger hospitals with greater stockpiles. Unfortunately for those who were referred, this solution frequently failed, and they were sent back after only a few weeks. Dispensing expired medication also occurred. A participant related an argument that he had with a service provider over outdated medication:

He said it can still be used. But it was clear that the bottle was marked for an expired date on 31st August, while I was given the drugs on 15th August. I told him that the drugs are already expired. The staff is angry at me. They said they only have that stock left. I paid the service fee. I paid for it, yet I was given an expired drug. What if there are negative side effects for patients who take an expired drug? (01, TGW, Jakarta)

The study's more proactive participants reported finding ways to counter such ARV shortages. Tactics included borrowing the medication from a HIV-positive friend or partner, asking a close associate who worked at a clinic to appropriate the needed ARVs (possibly illegally), rationing unused medication, and going around the health care system. "When I knew there was going to be a shortage of ARVs," one participant explained, "I immediately bought them online for myself with my own money." (11, MSM, Bali).

In addition to ARV medication shortages, other impediments to ARV adherence that participants reported included the expense of traveling to a clinic for refills given their reduced incomes, fear of being exposed to COVID-19 during a clinic visit, and medication fatigue.

It's not that I don't want to take my ARVs, but I don't have any. Before the pandemics we already had to pay an administration fee and it's harder now. I need to go to the clinic 3 to 4 times a month, with additional cost for transportation. Therefore, I sometimes decide not to take the medication. I'll just plan to go to the clinic next month instead. (02, PWUD, Jakarta)

Social support during the pandemic

Clearly coping with the stress and restrictions imposed by the COVID-19 pandemic proved an enormous challenge for PLWH. In the face of high stress and deprivation, it is not unusual for people including our study participants to turn to informal and/or formal sources

of support to help meet their emotional, financial, and/or other needs.

Informal sources of support: family, friends, and key population peers

Participants described drawing upon their familial and personal social networks including HIV key population peers for emotional, instrumental, and/or informational support.

Emotional support provided by family and close social network relationships consisted of conveying to participants, and sometimes mutually sharing, supportive feelings such as empathy, affect, and reassurance that things will get better. Participants reported feeling less fearful and more hopeful about their lives and future after sharing their problems or worries with someone even if nothing significant changed. One respondent explained, “I tell my friends if there are problems even though sometimes, I don’t find a solution.” (03, FSW, Jakarta).

Instrumental support consisted of tangible support such as money, food, material goods, temporary housing, and care when ill. Financial help was the most frequently mentioned form of instrumental support. As one informant confessed, “I borrow from family sometimes to cover my daily needs. I don’t have any choice.” (06, PWUD, Jakarta). Or as another informant asked rhetorically and then self-answered: “What do you do if you’re in a tight spot? I have to borrow some money from others.” (07, FSW, Bali).

Informational support took the form of being given advice or engaging in a mutual sharing of problems and possibly solutions. An informant described the good advice that she received from a peer:

I have a friend in my peer support group who is also from the community who suggested that ‘it’s better for us to sell roasted rice around than do nothing.’ So I said, “Let’s do it! Let’s sell rice around.” Thank God, I was helped and supported by the transgender community. And well, even though I only earn a little, I have had help like that. (01, TGW, Jakarta)

As evidenced by informants’ accounts, family, friends, and members of social networks frequently functioned as crucial sources of informal support, but not always. Participants told of parents or family who lived too far away to be of much help or who had their own daunting challenges to overcome. In some instances, familial relationships were strained and unavailable due to negative judgements about a participant’s behavior such as using illicit drugs, selling sex, or engaging in same sex behavior. As one transgender woman lamented about

her family’s rejection of her, “No one cares about me, no one cares.” (01, TGW, Jakarta).

Formal sources of social support: government and community organizations

Participants also reported instances of receiving COVID-related formal assistance from the Indonesian government. For example, one participant reported receiving a cash transfer as a “pre-employment allowance” while he searched for work. (01, MSM, Bali). Local municipalities also provided conditional cash allowances (*bantuan langsung tunai*), food, and other supplies to PLWH who were in dire need. Unfortunately, from recipients’ perspective, the duration of such support could prove far too brief.

I once received rice and a few supplies from a Bekasi City government agency. It was enough for 4-5 days and maybe up to a week. But it was for one time only. When the government gives out these items, it doesn’t think about duration and how long they will last. But I shouldn’t blame the government in the city where I live. I should instead say thank you. (02, PWUD, Jakarta)

NGOs and peer groups organized around advocacy and support for HIV key populations frequently functioned as vital safety nets for their members. Assistance varied but tended to take the form of grocery and food distributions, cash allowances, meals served at food kitchens, and help in applying for public aid. Such formal assistance proved especially valuable to participants who found it difficult-to-nearly impossible on their own to compile the paperwork or documentation needed to establish their eligibility for government support.

Challenges to health service use

The correlates of the COVID-19 lockdown and mandated social distancing created numerous impediments for participants in accessing not only COVID-19 services but also HIV and other medical care. Financial strain due to diminished income made it especially difficult to meet the medical and transportation costs of accessing medication for HIV. A transgender woman described the difficulties that she faced in accessing the ARV medication that she needed:

One of my barriers to services is the cost constraint. I often borrow from friends for [the necessary clinic] registration fee. I also don’t have the money to go. That’s why I want money from the government or from PLHIV health services agencies [in the form of] transport compensation or something like that for people like us. There are so many people like me. (06, TGW, Bali)

Similar financial and practical challenges could hinder access and the use of mental health services needed to counter the effects of severe stress, anxiety, sleeplessness, and other debilitating conditions due to COVID-19. While participants who suffered from these disorders expressed the desire to access mental health services, few knew how to do so. One participant explained, “We don’t know about mental health services, so we’re confused.” (10, MSM, Jakarta) “And it’s expensive,” complained another informant who didn’t know about the availability of community free services. (11, MSM, Bali). In addition, the value of psychological counseling and mental health services were sometimes questioned or not seen as being needed. “In my opinion, it’s not that convincing.” (01, MSM, Bali) “I have my own healing system,” another participant explained. (14, MSM, Jakarta).

Participants were well-aware of the social stigma surrounding HIV and their PLWH status. They feared that contracting COVID-19 would become an additional source of social censure should they acquire it. One participant mused, “The stigma of getting the coronavirus is harsher than getting HIV.” (14, PWID, Bali). Another asked quizzically:

If I died because of COVID, what would happen? It’s a sin to die because of COVID and my family would be isolated by the neighborhood. And if I get COVID, I am afraid I will be evicted or something like that. (08, TGW, Jakarta)

In seeking medical and mental health services for COVID, informants feared that they would encounter negative judgements by medical staff because of their HIV status, sexual behavior, drug use, and/or livelihood as a sex worker. Transgender women, for example, uniformly reported great difficulty identifying mental health providers who were sensitive to transgender issues. Engaging in same sex behavior also was seen to potentially evoke provider condemnation. One male participant who has sex with men reported a past instance of negative counseling about his sexuality that continued to hurt him:

When I was in Jakarta, I was exposed for the first time to information about sexuality. So, I tried to see a psychologist for consultation about why I am gay. [I asked] why am I in conflict with myself? Instead of helping me to understand, she judged me instead by saying, “Remember that God created men and women. Your nature is as a man, and yes, you must carry out nature. You can’t violate nature like that.” I felt judged and a bit traumatized by that.” (17, MSM, Jakarta)

As a result of this experience, he was reluctant to seek both HIV and COVID-19 medical services out of fear of a similar emotionally painful occurrence.

Yet not all informant encounters with mental health and counseling services during the COVID-19 pandemic turned out bad as participants sometimes anticipated. A female participant who sold sex for a living reported that, “I feel quite satisfied with the services that I received. The doctor seemed familiar, friendly, and liked to ask and answer questions.” (15, FSW, Bali) Another informant who overcame his initial reluctance acknowledged that receiving counselling for depression from a professional psychologist during the COVID-19 pandemic helped him to overcome internalized negative judgements about being HIV-positive that drove him to contemplate taking his own life.

It’s fun! I now know my weaknesses and what I should do. I skipped counseling when I found out I had HIV. I would wake up every Saturday morning wanting to kill myself over all kinds of things. I came to know [through counseling during COVID-19] what made me sabotage myself like that. So far, I’m very satisfied. (11, MSM, Bali)

Discussion

This study is one of the few to examine the impact of the global COVID-19 pandemic on the lived experiences of PLWH in Southeast Asia. Its results add to a growing body of findings similarly reported by other COVID-19 studies throughout the globe [3], which are now confirmed as similar for Indonesia. The COVID-19 pandemic undoubtedly has exerted a strong negative impact on the general populace of all countries, including individuals coping with a chronic illness within them, but its syndemic effects on PLWH add an additional psychosocial, economic, and clinical burden on the health and well-being of an already socially and often financially compromised vulnerable population [16]. The study’s sample of participants drawn from Indonesia’s four HIV key populations represents a broad set of voices recounting a plethora of COVID-19 consequences for this marginalized group.

From a public policy standpoint, the study’s findings point to the many latent consequences of government policies to curb the outbreak of an emerging pandemic through enforced social distancing and stay-at-home orders. Legal bans against traveling freely and policy restrictions against in-person meetings disrupted most regular social activities and employment practices. As reported by study participants, such prohibitions could

result in personal stress, anxiety, and symptoms of depression further triggered by loss of connectedness to others and uncertainty as to the future. Before the pandemic, HIV key populations in Indonesia were found to be highly vulnerable to mental health problems associated with their HIV status [17], frequent lack of a social support system [18] poor quality of life [19] and the effects of both enacted [21] and internalized stigma related to societal disapproval of their sexual behavior and/or gender identity [20]. The impact of COVID-19 on their life could further exacerbate these existing mental health challenges [21], worsen mental health outcomes [22], and increase their vulnerability to mental illness [23]. Coping with the pandemic's challenges also could motivate detrimental health practices such as increased smoking behavior, unhealthy eating habits, and adoption or increase in illicit drug use. Yet when their accounts are viewed overall, participants showed evidence of considerable fortitude and resourcefulness in meeting the many challenges of living within the financial, psychosocial, and physical constraints of a deadly epidemic. Going around the system to get ARVs when unavailable and tapping into informal social support from family, friends, and HIV-positive peers proved essential in assisting them to persevere as did formal support when available through government subsidies and NGO assistance.

Recognizing from the start of the pandemic that a public health lockdown could prove psychosocially devastating to its population, the Indonesian government instituted a free online counseling initiative (SEJIWA) to assist individuals experiencing severe mental health distress. Few participants in this study, however, knew of this resource and none had used it. Possibly this lack of help-seeking can be traced to wanting to avoid being negatively judged by health care workers for their HIV status and/or sexual practices. Studies conducted in Indonesia, Pakistan, and the United Kingdom [5, 24, 25] that admitting to health workers of being HIV seropositive can translate into lesser COVID-related medical care [25–27].

In addition to offering online counseling, the government also instituted a series of cash and food subsidy programs for the poor and recently unemployed due to COVID-19. While the pandemic triggered an economic crisis for multiple individuals and families across Indonesia [26, 27], as a socially marginalized and largely disadvantaged group, PLHA were among the more financially impacted and severely impoverished populations [27, 28]. Meanwhile, difficulties in amassing and completing the documentation and paperwork required to successfully apply for government assistance left some of the study's participants without this formal help. This finding is consistent with other research showing that key populations

in Indonesia often are excluded from access to social protection programs for numerous reasons including not having a personal ID card, a family card, and/or a reference letter from a civil office [28–30]. Participants reported that NGOs could prove highly valuable in helping to successfully meet such government requirements for assistance.

The country's lockdown and travel restrictions during the start of the COVID-19 pandemic posed multiple challenges for participants in obtaining ART medication. While all ART procurement and societal distribution is handled by the Indonesian Ministry of Health, the drugs themselves are imported from countries outside of Indonesia [31]. Indonesia's national COVID travel restrictions and isolation policies resulted in major disruptions of ARV supply chains into the country and across its vast archipelago [32]. As a result, HIV clinics struggled to deliver quality HIV treatment while coping with spotty medication deliveries and dwindling ARV supplies. Out of necessity, providers found themselves forced to ration dosages or switch to less preferred treatment regimens [33], and possibly even to dispense dated medications as one of our respondents found. Yet, as also recounted, some participants found ways to go around the system to obtain the medication they needed.

Fortunately for the study's participants, finding money to purchase ARVs was not a problem. The Indonesian government provides free ARV medication for PLWH, and participants reported fair to good adherence in taking it. Yet maintaining consistent adherence could prove highly challenging for Indonesia's PLWH due to clinics' limited supplies at the start of the pandemic, medical registration costs that had to be paid to receive free government treatment, and the expenses and added burden of regular clinic visits during the lockdown. Not unlike the experience common with individuals living with HIV prior to COVID-19 [34], medication fatigue also could exert a toll on consistent HIV medication use. Similar challenges to maintaining ARV adherence in Indonesia during the pandemic have been reported in multiple countries including China [35], Mexico [36], Vietnam [1, 37]; and much of Asia [38].

The scientific literature contains numerous recommendations and effective strategies for adoption by countries, health systems, and providers to help support ARV adherence during a disease pandemic or period of national crisis. These include instituting access to refills by mail and drive-through refill booths, providing patients with extra medication and extended ARV refills to obviate transportation problems and to tide them over during periods of shortage, heightened coordination between local CDC clinics and hospitals to expand existing refill sites, and mental health online counselling

to remove psychological barriers to accessing ARV services [1, 35, 39, 40]. In Indonesia, motorcycle ARV home delivery proved a successful distribution strategy as private motorcycle transportation companies were legally exempt from the country's large-scale social restrictions because their general services were seen as essential [41].

Much of the current body of HIV COVID-19 research reports on the impact of the COVID-19 pandemic during its first year. Since then, other variations of the virus have emerged, public health policies in many countries have shifted, and vaccines and other medications have been developed to prevent or reduce COVID-19-related mortality and morbidity. Additional research is needed to study the impact of the pandemic on PLWH under such evolving circumstances, and studies also are needed that investigate and identify factors that predict successful resilience to its effects. Clinical research shows that people who contract COVID-19 are subject to a possible post-infection sequelae of mental and/or physical health disorders. Sometimes referred to as the pandemic's "long haulers"[42], the long-term effects of post-COVID-19 infection on the health, behavior, and well-being of PLWH beg to be investigated. Participants also spoke of the potentially stigmatizing effects of testing positive for COVID-19 as members of a HIV key population. Both research and effective interventions are needed that mitigate the intersectional stigma for PLWH of having contracted both HIV and COVID-19. Finally, in addition to government subsidies, formal support through NGOs and informal support from family, friends, and peers proved an essential source of help for PLWH during the pandemic. Yet from the paucity of studies reported in the scientific literature, little is known of the impact of providing such support on these key providers.

Limitations of the study

The results of this research are based on data gained from a convenience sample of 22 HIV-positive participants recruited from 9 HIV NGOs approximately 9 months after the government instituted its lockdown policy. Its findings may not fully generalize to PLWH whom this recruitment method failed to reach or who chose not to participate in the study. Neither do the study's results necessarily represent what these same participants or other PLWH may have experienced over time as the pandemic unfolded and its effects possibly changed. Also without a comparison sample of people not infected with HIV, it is impossible to know to what extent the study's findings are unique to the syndemic of living with HIV while confronting the health and psychosocial demands of COVID-19 as an intersecting pandemic. In addition, the study's participant recruitment efforts solely targeted urban areas whereas a recent study found that PLWH residing in rural

areas tend to experience a poorer quality of life when compared to those living in urban settings [5].

Finally, the analytic categorization of participants according to membership within a particular HIV key population was based on how they self-identified when seeking NGO services. Eligibility for PLWH benefits as established by government and most NGO regulations typically assign clients as being solely members of one of four HIV risk groups: FSW, TGW, MSM, or PWUD. The study's initial data analysis sought to compare similarities and differences in COVID-19 experience between the four key populations. While potentially informative, such comparative analyses proved impossible as self-identifying as a member of one key population did not rule out engaging in the same sex or drug behavior that defined another. For example, engaging in illicit drug use and/or transactional sex was not uncommon among members of all four key populations, and same sex behavior was not solely confined to men who self-identified as MSM. Such instances of similar sex and/or drug behavior across PLWH key populations speak to the need for caution when seeking analytically to compare individuals defined as members of one HIV and/or COVID-19 vulnerable key population as being experientially and/or behaviorally different in sex, drug use, or other possible critical factors from members of another.

Conclusions

In May 2023, the World Health Organization announced that COVID-19 no longer constitutes a public health emergency of international concern although remaining a global health threat [43]. As with numerous other countries, the pandemic in Indonesia appears to be substantially waning as newly developed vaccines against infection exert their effects [6]. Nonetheless, mutations of dangerous new variations of COVID-19 remain a constant threat. Also, over the last 50 years, the world increasingly has seen the emergence and reemergence of viral and bacterial pandemics that pose serious mortality and morbidity threats [44]. In addition to HIV, these include ZIKA, SARS (Severe Acute Respiratory Syndrome), MERS (Middle East Respiratory Syndrome), Ebola, and Disease X (a yet unknown future pathogen). Although seemingly effective epidemiologically, the results of this study point to the latent consequences of government attempts to curb the spread of a pandemic through public health lockdowns and enforced policies of physical separation between citizens. The participants' experiences are vivid reminders of the importance of ensuring that public safety nets for PLWH are available if needed that supplement and assist more informal sources of instrumental and psychosocial support provided by family, friends, and others in the community.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-024-11227-1>.

Supplementary Material 1.

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Authors' contributions

Conceptualization: ES., L.P.L.W., and P.P.J.; Methodology: ES., P.P.J.; Software: D. and M.D.N.; Validation: J.L. and L.P.L.W., Formal Analysis: ES. and J.L.; Investigation: B.D.K.W., D., M.D.N.; Resources: B.D.K.W.; Data Curation: D., L.P.L.W., and M.D.N.; Writing- Original Draft Preparation, ES.; Review and Editing: J.L., L.P.L.W., P.P.J.; Supervision: J.L.; Project Administration: B.D.K.W.; Funding Acquisition: J.L. and P.P.J. All authors have read and agreed to the published version of the manuscript.

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Availability of data and materials

To maintain research confidentiality and protect the privacy of the HIV key population members who participated in its in-depth interviews, the study's data set will not be made publicly available.

Declarations

Ethics approval and consent to participate

The study has been approved by the Human Research Ethics Committee of the Faculty of Medicine, Udayana University/Sanglah Hospital with ethical clearance number 1806/UN14.2.2.VII.14/LT/2020. Informed consent was obtained from all individual participants included in the study. All methods were carried out in strict accordance with relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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