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COVID-19: SURVIVING A PANDEMIC COVID-19: Sansiring a Paralemic provides critical insights into survival manager. suployed by communities and individuals around the world during the pundent. A central question cance this pandemic began has been how to survive a That question has applied not just to staying alive, but also to staying health, both physically and mountally. Survival in certainly key, but surviving, and what the means, is that critical. The scholarship included in this volume will take a closer look at whit it means to survive by addressing such muce as the importance of other ey in vacous uptake, the gendered and metalized impacts of the pandemic the report in these with disabilities, questions of food security, and what it means to gree-Drawing on the expertise of scholars from around the world, the work procured here represents a remarkable diversity and quality of impassioned scholarship on the input of CCVID-19 and is a timely and critical advance in knowledge related to the pundemic. J. Michael Ryan is an award-winning teacher who has held academic politions at rep-canked universities across five continents. He is currently Associate Profesor of Sociology at Nazarbayev University (Kazakhstan) and has previously held a aden-Position in Egypt. Portugal, Ecuador, and the USA. Before returning to scalenia. On Ryan worked as a research methodologist at the National Center for Health Verber (which a part of the Centers for Disease Control and Programmi Washington, DC, where he led multiple projects samed at improving named Sanated survey methodology. He is the author (with Senera Nanda) of COVED-19 Sand Inspection and Human Psychiatric (Routledge 2022) and (co-lector of more than 15 volumes including COID-19: Global Pandenic, Seattl Revent. Lest year Schutzer (Routledge 2021), COVID-19: Global Penderut, Seiter Delard August Schutzer (Routledge 2021), COVID-19: Social Consequence and Outledge 2021). Adaptives (Routledge 2021), COVID-19, Sanat Consquere and State (Routledge 2021), and Case Consists in Society (Wiley 2019). He is also be found to the Constant of Society (Wiley 2019). the the founding editor of Routledge's The COVID-19 Pankown Series

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xiv Contributors

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DISCLOSING ONE'S HIV STATUS DURING INDONESIA'S COVID-19 PANDEMIC

Challenges Faced by Mothers

Najmah, Kusnan, Tom Graham Davies, and Sharyn Graham Davies

Introduction

My daughter, Via (living with HIV) (11 years old), wants to be a police officer. She always mentions this ambition to her friends and teachers at school. But can she pursue this ambition? I am unsure [voice sobs]. Via always asks me why she needs to take these medicines (anti-retroviral medicines, ARV). Her questions make me sad. However, I tell her it is our destiny; it is our fate (uidah nasil) kito). We have to keep taking our ARV medicines, I tell her. I need to take mine too. I need to fight as I have six children. If I stop taking ARV medicines, I will pass away (potos nyano). It would be a pity for my children."

(Oneng, Jimuary 2021)

Oneng passed away from HIV complications (possibly COVID-19 related) in June 2021. As a widow, she left behind six children. She was the sole income carner, meaning that her children are now facing difficult financial hardship. When Oneng fell ill, she knew she should go to the hospital for treatment, but she was too afraid to go. She believed that if she went to the hospital, she would contract COVID-19, and if she was hospitalized, she would be tested for COVID-19 and test positive. Oneng thus died at home, and the precise cause of death remains

Oneng's story of dying from HIV complications in the time of COVID-19 unknown. is sadly not exceptional in Indonesia. Widi, a pregnant woman living with HIV, shared a similar story. Like Oneng, Widi avoided visiting the hospital when she was ready to give burth for fear of contracting COVID-19. At any other time, Widi would have sought help from the prevention of mother-to-child transmission (PMTCT) services at her public hospital in the central city of Palembang Widt knew that this service was the best way to avoid transmitting HIV to her

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unborn baby. Like Oneng. Widi believed that hospitals had the highest unborn baby. Like Oneng. Widi believed that hospitals had the highest unborn baby. Like Oneng. Widi believed that hospitals had the highest hospitals and had the highest head to disclose her HIV. unborn baby. Like Oneng. With Sumatra. With thus gave birth to her bay and COVID-19 patients in South Sumatra. With the gave birth to her bay and covid and while she felt able to disclose her HIV status. COVID-19 patients in South Sou

Prior to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many year across to COVID-19, both Oneng and With had for many years across to COVID-19, both Oneng and With had for many years across to COVID-19, both Oneng and With had for many years across to COVID-19, both Oneng and With had for many years across to COVID-19, both Oneng and With had for many years across to COVID-19, both Oneng and COVID-19, both Oneng Peior to COVID-19, both managed their HIV using ARVs and accessed PMTCT services when the managed their design to the COVID-19 pandemic affected their design to their babies. But the COVID-19 pandemic affected their design to their babies but the COVID-19 pandemic affected their design to their babies. But the COVID-19 pandemic affected their design to their babies. their babies. But the COVID-19 was a tree they long to hospital because they long health conditions. COVID-19 was a tree. help. Women with underlying health conditions, COVID-19 was a particular as people with underlying health conditions, COVID-19 was a particular as to their well-being. It was not just contracting COVID-19, however, the last their well-being are from hospitals and thus access to Any mothers hving with HIV away from hospitals and thus access to ARV modes. These mothers were also afraid of disclosing their HIV status. With housing p times thanks of the state of th away from the hospital without treatment. As such, some women living with delivered their babies in hospital without disclosing their HIV status. They is this would put themselves, their baby, and the medical staff at risk, but they go other option.

Parallels may be drawn between Oneng's and Widi's stories, as both lighter the cultural silence surrounding HIV in Indonesia and how HIV intersective COVID-19. Both HIV and COVID-19 are veiled by a culture of denial will go eraments, and even health officials, downplaying their respective danger (Nea and Ryan 2023). Sadly, this silence has resulted in increased suffering and premable deaths. There is also a gendered aspect to this salence. For instance, manufactured narratives in Indonesia declare that "good" wives and mothers do not get nictel with HIV As such, disclosing one's HIV status classifies a woman ipso face as "bad" woman (e.g., someone who has had high-risk sexual intercourse and/or min venous drug use) (Najmah, Davies, and Andajan 2020). This classification exactors the already difficult health and economic challenges experienced by women living HIV. Assuch, some women "choose" to stay silent about their HIV status whenthy " to access pregnancy care. The culture of silence also feeds into and exacerbacidad of COVID-19, which are then compounded by the ill-treatment by health services providers of women living with HIV. The women living with HIV we can't know during this research told us of their lives. Sadly, their stories include a god deal of suffering and of economic struggle to meet daily necessines, as well in its togras of living with HIV, in a time of COVID-19. This chapter examines in mequalines in gender and health care intersect with a lack of support services in

women living with HIV that exclude women from the help they need. Within this analysis, we explore two key themes. The first theme examines is: COVID-19 increases the risk of death from HIV in Indonesia. The second their investigates how the silence surrounding HIV results in the ill-treatment of wones living with HIV in health service settings. The methodology guiding the resemb was feminat-paracipotory action research. The focus of the research was more alized women living with HIV in South Sumatra, Indonesia, and was conducted

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Research Setting and Method

Out research rate is located in Palendong, South Summa, Indonesia Palendong, Out described by the Banciusan Regimey to the north, rait, and sens and Muara pone and Ogan flir Regency to the south, Palernbang's area is 40,000 km², with a population of 1.7 million people in 2020 (Barlan Pusat Seatarth 2020). Palembang a divided into two main areas by the Mini River Schring flir and Schering Ulu. The average monthly income of a Palembang worker is approximately Rp 1.2 miljum (\$85 US in 2022), with about 200,000 or 11 percent of the population fiving on less than half of that, Rp 480,000 (about \$35 US per month, in April 2022) ICEIC 2019). While men and women over 15 years have nimilar screen to educayou, unpaid domestic work in the home is still largely undertaken by women, with about 92 percent of women doing the majority of domestic work (Miranda 2011). a high rate by OECD (Organisation for Economic Co-operation and Development) standards,

Palembang has 147 climics, hospitals, and public or community health center However, the ratio of health workers to population is low, at about 0.5 per 1000 population or about 2000 health workers for 1.7 million people. By way of compartion, the WHO recommends a threshold of 4,45 skilled health workers (physicians and nurses/midwives) per 1000 people in order to achieve universal health coverage (World Health Organization 2015). In terms of antenatal visits, the majority of women (about 90%) in 2020 made at least four visits. Contraceptive methods among married spouses are mainly progesterone injections, the pill, and implants (Gafor et al. 2020). In terms of HIV-related health services, in 2021, Falembang has four sexually transmitted infection (STI) chaics, 56 voluntary counselling and reseing (VCT) clinics, 38 HIV care, support, and treatment (CST) local health clinics (punkesmas) and hospitals, one methadone climic, and only two hospital-based HIV care and PMTCT services. Prior to COVID-19, antenstal HIV tests were provided in all 41 paskeimas in Palembang (Public Health Office of Palembang 2021).

This research project used a feminist participatory action research (FPAR) framework devised by Patricia Magnite (1987). Magnite highlights the importance of building trust, creating meaningful participation for women throughout the research process. and ensuring outcomes that include a collective cruscal consciousness that challenges oppressive attitudes, beliefs, and practices that may be deeply embedded in society We use FPAR to explore programs women living with HIV's experiences accessing bealthcure services, including antenatal care claring the COVID-19 pandemic

In line with FPAR, we use methods devised by the women to encourage what Magnine refers to as "deep voice" expression. We also employed observation, ethnography, online discussion groups and face-to-face meetings, and diary notes, as a form of triangulation. The interviews explored the experiences of 20 women live ing with HIV, who were either pregnant, or had been pregnant, or had a child been with HIV during the first year of the pandemic. The groups had an average age of 29, and their above-average monthly family income ranged between Rp 1,500,000 \$100 US) to Rp 4,000,000 (\$280 US).

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A Snapshot of HIV in Indonesia

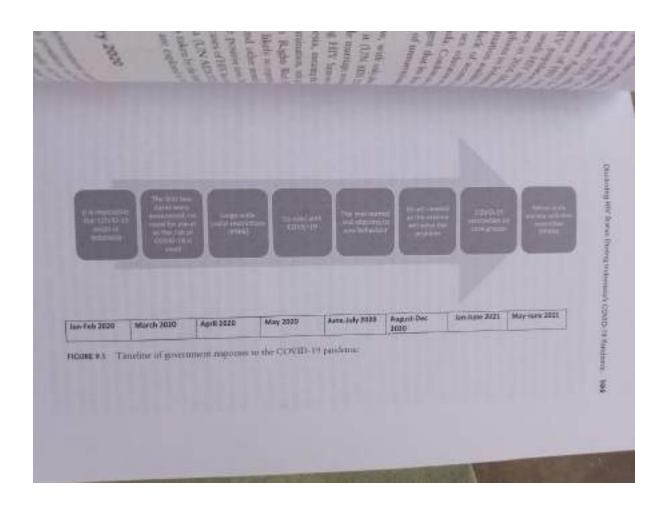
A Snapshot of People living with HIV are subject to significant obstacles and discretized to the WHO, out of the present population People living with Fit at WHO, out of the present population of the MHO, out of the present population of the MHO, out of the present population of the MHO, out of the present population of the present population of the MHO, out of the present population of the present populati Indonesia. According to the front over 670,000 people living with HDV to specific 2020, should be a specific 2020. non, there are currently over 100 on ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and HIV Data Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and Hub in ASIA Pacific 2020), advention of 2 percent (AIDS and Hub in ASIA Pacific 2020). ber may be grossly underreported. The United States Agency for lives, ber may be grossly unastroped that only 44 percent of HIV then as Development (USAID) suggests that only 44 percent of HIV then as Development (USAID). Two-thirds of the HIV population is not Development (USAID) 1921). Two-thirds of the HIV population is income in Indonesia (USAID 2021). Two-thirds of the HIV population is income in Indonesia (USAID 2021). third is female. The number of pregnant women with HIV increased third is female. The number of pregnant women with HIV increased to the property of the pregnant women with HIV increased to the pregnant women with the pregnant w cent from over 15,000 in 2012 to over 19,000 cases in 2016 (Markey 4) 2018). There are approximately 220,000 AIDS orphans in Indonesa Alig nesia 2016). Broadly, there is a poor level of information available to lake about how HIV is transmitted and treated. The lack of accorate information compounded by the almost complete absence of sex education in Indoless many officials oppose its inclusion in school curricula. Condom we u les sexually active people in Indonesia. Estimates suggest that less than 5 people married women use condoms and only 25 percent of unmarried male able do [Putra et al. 2018].

The availability of anti-retroviral treatment is low, with only about 20 people living with HIV (PLHIV) able to access it (UN AIDS 2020, The considerable stigms and condemnation of sex outside marriage, resulting a light rates of STD transmission (Wibawa 2019), including HIV Same-sex relations are generally met with public disapproval in Indonesia, meaning that LGBTQ-people face significant public and law-based discrimination, with gw this is health center frequently raided by police (Human Rights Watch 2018, the 2015). Similarly, people living with HIV are more likely to expension the directed at them and have higher rates of suicide and other mental health of (Breuer et al. 2011; Sherr et al. 2011). There is some positive news Dut come efforts to combat HIV, the reported number of new cases of HIV has deducted 38,000 in 2015 to about 28,000 in 2020 in Indonesia (UN AIDS 2020).

Living with HIV negatively intersects with actions taken by the Indonesia F emment to address COVID-19, examples of which are explored in the ideal stones of women living with HIV.

Indonesia's Response to COVID-19 (January 2020 to June 2021)

Figure 9.1 tracks changes in how the Indonesian government responded e is challenges presented by COVID-19, moving from a position of outsight to through to large-scale social restrictions, overselling the role of vaccination finally, reducing COVID-19 prevention to the level of individual action the benefit of hindsight, it is easy to be critical of the failures of the Indonesia government.



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The Indonesian government's initial response to the COVID-19 Page. The Indonesian government with the impact of this deadly business a lost opportunity to successfully reduce the impact of this deadly division in the impacts on women living with HIV Statements. a lost opportunity to macrosses, the strong with HIV Statement first of its impacts on women living with HIV Statement for the possibility that Covers and larly in light of its impact.

Indonesian government initially denied the possibility that COVID-19. at all in Indonesia. Following the first confirmed cases, the government at all in Indonesia. Following the existence of the disease to down at all in Indonesia. Following the existence of the disease to downplace then changed from denying the existence of the disease to downplace to then changed from denying the case's lethality. Controversy autrounded the government with statement to case's lethality. ease's lethality. Controversy autominuters and legislative increases 2020, the minuter of transportation large impact. For example, in February 2020, the minuter of transportation large impact. stated, "Indonesian people are immune to Corona because we like to each to be and other ingredients wrapped in banana leaves]" (Redaku 2020). Innitial then exposed to COVID-19 and treated twice for the virus Ostoria 300

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By April 2020, the Indonesian government accepted the reality of Conand introduced large-scale social restrictions along the lines of many obey (Pembatasan sonal berskala besar, PSBB). There were six types of server see These included (1) studying and working outside of the home; (2) migroup ties; (3) activities in public spaces; (4) social and cultural activities; (5) to tion; and (6) other activities, mainly related to defence and security

The speed of communicating directives requiring public transfers reflected the malaise of central government implementation. Policy comme tion between layers of government, from central to province and finds to the city level, were sluggish. Despite modern, instantaneous commitechnology, the timeframe between central government policy announces local government officials receiving policy directives could be measured a --By this time, both the disease and the policies addressing us impact an effect moved on.

During one of these changes, at the beginning of June 2020, the later government introduced the phrase "the new normal era," which encaps notion of accepting the inevitability of the disease and adapting to charge ing with COVID-19 (adaptasi kebiasaan bani). At the time, case of COVD-19 increased significantly, and the economic impacts of social ristriction beauti felt at both the central government and individual levels (Breshi 2023)

The adoption of the new normal suggests that the central government under significant economic pressure to favour less economically damaging with the cost of health impacts being, once again, downplayed (City Res) From August 2020, the government narrative changed again to dispense at tion about COVID-19 vaccine trials, even though the Indonesian government aware that vaccination would not, at that point, end the pandemic Imagazine health workers were shared on social media, suggesting a panacea for the Collaboration (Naimah, December 19) 19 pandemic (Najmah, Davies, and Kusnan 2021; Sanford, Smith, and Bloth By May 2021, the government of the Sanford Smith, and Box and Sanford Smith, and Smith, and Sanford Smith, and Smith, an By May 2021, the government's narrative was modified again to encourage scale public activity restriction. scale public activity restriction (PDVA4), particularly after number of

(Chookajorn et al. 2021). The Delta variant also led to a significant of COVID-19 cases in Indonesia (BBC News 2021). Prior to obst countries (CDVID-19 cases in Indonesia (BBC News 2021), brior to the Dela united daily reported cases ranged from between 5000 and 10,000 page. and the court of cases ranged from between \$5000 and 10,000. By the end of duly report of new cases reached 30,000 to 50,000 duly.

the approach returned to semething under to PSBI. Central government this approach governors and municipality leaders to mobilize actions at the property directed is a schools, workplaces, retaurants, markets, and praying a course 2021). However, the unplementation of this policy are advided level. However, the implementation of this policy was poorly manand coordinated, and the focus was still an economic one, with the minimeand the state affairs being replaced by the minister of maritime and investment affairs during the Eads celebration, the Islamic day the continuous affairs

Smilerly, during the End⁴ celebration, the Islamic day that takes place at the end of samuely, an incomplete and highly telling statement was made or holy independent Joko Widodo. Despite social distancing and physical morning to the encouraged the Indonesian postper interiories, he encouraged the Indonesian people to do "pulmy kunpong". arming to break physical distancing restrictions and visit their hometowns during arining boliday. Similarly, the minister of tourism and creative economy, Sandiaga the undermined his government's own goals of restricting movement by reopening oppular tourism descriptions such as Buli, and another minister allowed the entry of Chinese health workers into Indonesia (Najmah, Davies, and Kusnan 2021)

Be July 2021, despite obvious evidence to the contrary, denial once again became the watchword by the minister of maritime and investment affairs, Lubar Busar Pandjattan, who confidently proclaimed that COVID-19 in Indonesia was now under control. However, a few days later, he made an about-face, informng the general public that the Delta variant could not be effectively dealt with (Amagerah 2021). These are just a few examples of the more glaring and inconstant newages proclaimed by high-ranking Indonesian officials. We now turn to the individual impacts of these policies

A Battle Lost: Life and Death Among Women Living With HIV During COVID-19

The first author knew Oneng for the last three years of her life and witnessed tha considerable effort it took for her to survive the death of her husband, raise six dildren, be a breadwinner, and access ARV thorapy. She represented the concept of a traditional Indonesian housewife or the namely tangen

During our interviews. Oneng spoke of the lack of support from health and Sungmernmental organization (NGO) workers for her condition. In one instance, the execution of the execution (NGO) workers for her condition in the interest her the expressed her frustration and anger when one NGO worker ignored her Inquest for help to get ARV medication from the hospital. When her condition Workened, she sought a consultation during her monthly visit to the HIV centre the public hospital. Her deteriorating condition proved extremely challenging for her as you The let as restrictions in health facilities during the pandemic led to the introduc-The of protocols that changed how doctors and patients interacted. The doctor she was to could be a could be supposed to could be supposed. Pole in could not check her directly, kept a physical distance and only provided

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her with a prescription, and alrested the combination of her ARN to make the effects. She added that some doctors who had previously treated be in complayed elsewhere, attending to COVID-19 patients, and were seeing their regular potents. As a result, Oneng defaced her much-medical had and reserved to self-neutrinost by combining burked neclarities with the After live condition womened even more. Oneng decided to visit the room in the public hospital. She revealed the following:

And right now, I feel tick because of increating stemach and I in an emergency room in a public hospital. Health worken percent resument, therefore I was motivated to recover. Health worken that living with HIV, and I had to undergo some procedures, including in the emergency room. Then, thiring my hospitalization I unless threstound checks. So many doctors cared for me, and I believe the result of help from an HIV NGO who begged for me to be send (Outry) that y notes shared with the just matter And I.

Women living weth HIV in this study shared with us the energie to go in care. HIV service precision decreased during the pandemic, as model essays were stretched. The already present alternation felt by women subject in Hisstigms was worsened by COVID-19 protocols such as physical distancing beautiful. patients living with HIV and doctors. In score instances, tables were used a terers to minimize contact between HIV-positive women and health worker a VI because of COVID-19 concerns. Before the pandernic, women living with would normally consult doctors without any separation and would in codes counselling mom, interestingly, physical reparation was not carried on is a manufactured on its distribution of the counselling mom. who had been well trained for HIV programs (Najmah observation dame)! fieldwork, 2017-2018). However, physical distancing became the norm arms paraderme (Romania 2023). With the shortage of health worken, well-month doctors who normally provided HIV therapy had to double up thus role a provided HIV therapy had to double up thus role as practitioners treating COVID-19. Consequently, the limited acres to HIV also health specialists compounded the reluctance of women living with HIV 12 po care, even when they were feeling extremely sick. Oneng spoke of her experience

The doctor who has a role in HIV treatment also has another nile a risk ing COVID-19. Therefore, he was overworked and not able in greater help or provide consultation. There was no chest check or other dreater call check-ups. The doctor only listened to our symptoms and then my drug. That was all. When my mouth was fall of scurvy, the discount gested gargling with water and salt, and there was no other numbers is what medicine I should take or other suggestions. I was disquestionally asked myself why I visited the HIV facilities. I sit at a discovered

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I never been asked by the doctor. The health worker who asked me was the pharmacist who provided our ARV medicine. How are you, mon? Do you pharmacus of the pharma have my sysong are [too] busy to discuss on their own. When I saw them, I said I did for are possible and symptoms. I only felt fixed and got a hearbache. And I took my purdicine and went home.

(Edd in a focus group distriction)

The last statement made by Oneng in April of 2021, two months before the and is about health services and NGO participation when they finally enabled her in acces health services. While the authors applaud her bravery, and despite her memore treatment at the end of her life, we cannot help but think that her death night have been prevented had she been given a timelier intervention.

After Oneng's funeral, the first author visited Oneng's family and experienced first-hand how the impacts of scarce medical resources, due to COVID, can extend to wider familial networks. Out of Oneng's six children, Ona was the only one the took care of her mother in hospital, and she added how deeply distressing it as to see her mother in such a state and on so many medications. Had she been pur the attention she needed, it might have been avoided

Women living with HIV may suffer from HIV drug resistance as ARVs may not work well and lead to opportunistic infection, like toxoplasmosis or gastritis Bisvariju 2021). As researchers, we directly experienced both the hopelessness experienced by affected individuals and its impact on their wider families. We use his to highlight the tension between the struggle to gain access to appropriate HIV care and the pain borne by women living with HIV caused by the retasking

if medical professionals during the pandemic The prior statement highlights the double burden experienced by women living with HIV who have other underlying health conditions (opportunistic infection). when subject to the negative consequences of COVID-19 related policies. The tombination of a weakened immune system along with the fear and uncertainty of becoming infected with COVID-19 from health facilities results in fewer women wrking treatment and, therefore, lower life expectancy, as well as increasing the risk of solds. One

Furthermore, the low economic status of women like Oneng is compounded health at of under HIV transmission (May 2017). by health disparities (Schultz 2023) such as the nonavailability of doctors for these troups (CA). though (Chenneville et al. 2020). Worryingly, in some cases self-treatment becomes the only rehe only perceived option for those who are too poor or too afraid to visit their leads send and to delayed care least service providers when they have HIV. These barriers lead to delayed care right and put women living with HIV at higher risk of death

The Triple Bind of COVID-19 Restrictions

COVID-19 restrictions were performed as strategies to reduce to COVID-19 restrictions with properties of the local covid of the local COVID-19. Initially, the government hospitals restricted health leading to tion, due to shortages of health workers, hospitals restricted health leading leading to the leading leadin mize COVID-19 transmission. Finally, social restrictions led to applicate the property of the covid of the property of the covid of the visits due to misinformation (Ryan 2023) about COVID-19 (exing a sering a s misdiagnoses. Unfortunately, the triple bind of COVID-19 rearing at a a missed opportunity to prevent HIV transmission among mothers and a missed opportunity to prevent HIV may not disclose their HIV a massed opportunity to plan the may not disclose their HIV starts to see the starts to see the second second see their second s

Widi (34-years-old from a low-income family, living in a village to be with the status to health street to be a second to be a Widi (34-years-old none) to disclose her HIV status to health services led a specific and the health services led a specific and not during, the pandemic. She worked in the health sector and an reconstruction of the pandemic and the pand providing peer support for women living with HIV in her case the half given birth as a mother living with HIV and was experienced enough to transmission to her first and second children by opting to deliver them by section in a public hospital in Palembang.

However, during the pandemic, she decided to deliver her child regulate her third pregnancy. She told us that every month her obstetrician chebral pregnancy, but in spite of her experience as an HIV advocate, the did as comfortable enough to disclose her HIV status, as she experienced directly nation by being denied treatment when she asked for a referral letter face therapy. We use her case to highlight the difficulties women living set 30 experience during the simple act of asking for health treatment in labora be those women from low socioeconomic status groups, who lack the chiam and cultural capital to articulate the need for treatment, the barret is insurmountable.

Because of these barriers, Widi decided to risk transmitting HIV to be disher local hospital. The discrimination she experienced was, however, as a to her local doctor and the public health institution. After the delivery, be how asked Widi to breastfeed her baby in the hospital, as he was afraid the saft at mother-in-law would discover her HIV status.

COVID-19 also imposed a travel barrier, as Widi expressed that the breaking COVID-19 distance restrictions by accessing PMTCT HIV sees Palembang, a four-hour journey by car from where she lived

I was initially hesitant to have my child (during pandemic) became in afraid that I might transmit HIV to my baby. I also had feats of COVIDand travel restrictions from my village to Palembang. You know the demic is a difficult time for us (including economic challenges). There is 80% chances that the control of the 80% chance that my child would be infected with HIV. However to band supports me in band supports me in treating our baby together if our baby geo HIV

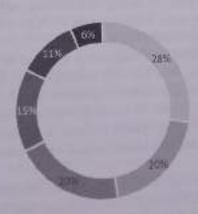
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Based on a survey conducted by the Global Fund from April to September 2020 Based on a second transfer in 32 countries in Asia and Africa, including Indianaat their are several key reasons why people have tended to avoid vinting health get there are seen the COVID-19 pandemic. Figure 9.2 shows that the main reasons in lude fear, mistrust, and uncertainty about the possibility of gening infected with coviD-19 from health services, limited public transportation due to mobility covering and the order of staying at home from the government (Global Fund 200. These perceived barriers were also found among the majority of women listing with HIV in this study and often resulted in nondisclosure of HIV status in health settings if the mothers needed to visit health services to access health

[In July 2020] Yes, I seek health services in a hospital, I do not disclose my HIV status. There is a strong stigma of being an HIV-positive mother, I cannot imagine disclosing my HIV status. I [really] do not want to open my HIV garus. Do you know why? I access the third-class facilities (there are 5-8 patients in a moom), and stigma is strong during the COVID-19 pandemic (every patient was suspected of having the virus). I was alone during my hospitalization, no companion (from family) was allowed. If I am open about my HIV status, people will not treat me (run from me); no one will take care



- Fear, inistrust, uncertaining of getting infected with COVID-18 from facility visits
- Disruption in public transportation
- * Lockdown or stay at home order
- Changes in necommendations to the public for mild illness and elective care
- · Others

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on to accessing HIV treatment during the COVID-19 pandemic

of me, inject the medicine for me. In my observation, health working and afraid of HIV compared to COVID-19.

(Delka, an informal intersection; read Silver on in Inside Indonesia; Najmah, Dunes, and Kuma 20;

Without proper sterification and damafectants, strict infection control, units, Without proper sterification and districts lead to missed opportunity, the intersected elements of these barriers lead to missed opportunity, the intersected elements of these barriers lead to missed opportunity, and other health workers and other prevent transmission to babies, but also to other health workers and other prevent transmission to babies, but also to other health workers and other prevent transmission to babies, but also to other health workers and other prevent transmission to babies, but also to other health workers and other prevents. (Misniya et al. 2010: Wysgowski et al. 2016). The COVID-19 pandemic radio (Missings et al. 2010) Wysgowski et al. 2010; also hunder ART continuous and testing fell 41 percent and PATCT acre.
Weiming 2020). For motatice, HIV testing fell 41 percent and PATCT acre. 20-40 percest between March and June 2020.

The disruption to HIV prevention services during the COVID-19 |Sec. including HIV screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for pregrant women, means more mothers are a standard model of the screening for t risk of not knowing their HIV status and more babies are at risk of pourse becoming infected with HIV (Global Fund 2020, Jising, Zhou, and Weining has However, the silence surrounding HIV in healthcare settings means makens obstetriciam often do not talk about HIV to pregnant patients. Come perdi all midwives and obstetricians recommend that pregnant women do as HIV thus reinforcing the stigms (Hopkyns and van den Hoven 2023; Mondal 2004). a result, many women may know their HIV status only after their children unfrom opportunistic infections, including malnutrition, and were offered as it test in the late stage in hospital. Unfortunately, COVID-19 restrictions also are the late diagnoses of their children's HIV status.

The impact of COVID-19 on diagnosis is reflected in Nur's store in One ber 2020. Nor needed to treat her first daughter, Anti (18 months old. ... became malnourished due to a medical condition. Despite being able to affect private hospital. Nor was unable to access appropriate services for her distri-Immediately, she was referred to a public hospital, as the doctor who specified her daughter's condition was unavailable because of the pandemic

The attending nurse explained that the doctor who specialized in until daughter's condition had other work to do and could not treat our dust Therefore, the hospital decided to refer my daughter to the public hospital at 10 pm. After arriving in the emergency room in the public hospital doctor explained the HIV status of my daughter (in a low tone of scient (Nur, an informal immer, 37)

After arriving at the public hospital, she recalled that a doctor called her and a regardly room. It was a constant emergency room. It was a crowded room, so the doctor disclosed to North child was living with HIV in a low tone of voice in the corner of the posts shocked to learn that she was infected with HIV", Nur said.

Nur's child is a moving example

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get offered an HIV test at any time from 2017 to 2020. After experiencing three get offend. Not was offered a complete blood test, which cost her Rp 3,000,000 and res \$210 in 2022), but the test did not include HIV terms. pager US \$210 in 2022), but the test did not include HIV terening.

per pily usung for pregnant women is theoremsally available in all public pealth services (puskesman) in Palembang, however not all pregnant women visit health services for their antenntal check. About 55 percent of all mothers go to perget undwises (Ministry of Health 2013), who do not offer oneste HIV tening maintenance and a half wars for the length of her pregnancy and the childs Missional and a half years, for the Indonesian health system to recogme the HIV status of a child born to a mother living with HIV. Nurt story also would the multifaceted barriers to accessing HIV treatment during the pandemic een after her child has been confirmed as living with HIV

Health workers are also refuctant to discuss HIV because a stigma may be attached es their institution as a whole. Health workers may attempt to protect the good passe of their hospital by diverting patients living with HIV to another specialist or loopital (Ha et al. 2013; Najmah 2019). Had Indonesia instituted a program to beter educate healthcare workers and work towards improved coordination between healthcare providers in the area of HIV, these issues and the suffering they cause may well have been avoided, or at least lessened (Knight and Bleckner 2023).

The Silence Surrounding HIV Combines With the Silence Surrounding COVID-19

While in certain simutions silence can be an effective strategy, at other times it can lead to suffering and death. One of the most interesting findings from this study is that there is a link between the silence surrounding HIV and the silence surroundng COVID-19. There are three intersecting elements to silencing first silencing and shame; second, silencing and morality; third; silencing and religious practices. Unfortunately, these silences contribute to delays in health-seeking behaviour, nondisclosure of HIV status by mothers living with HIV, and the concealment of HIV mans by patients in health treatment settings.

The notion of shame is a key aspect of Indonesian and Muslim culture. Muslim somen are in general taught to have a sense of shame, and being modest and shy is a part of the Muslim faith (man). In this study, unfortunately, shame prevented many of our respondents from disclosing their HIV status and accessing health tensices and led to psychological difficulties. At the individual level, women livthe with HIV in Indonesian society may feel asbarned, dirty, and not respected or needed, and at the community level, HIV is often seen as something people tenenal as punishment for acting immorally (DeWees and Miller 2023). Therehere, idence is one means to avoid feeling the shame of being exposed to negathe public attitudes, or silence is deployed when accessing much-needed health COVID-19 pandemic where they may not have the resources to help PLHIV. Interestingly, staying silent may be interpreted as acceptance of the unfairness of

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health services (Wong-Padoongpat and Barrier 2023) and m a form of dealth takdir, thus undermining public demand for improvements to treating type takdir, thus undermining public demand for improvements to treating type

Sharne is also a moral value and is instructionalized in health services in health services in his best (Bennert 2016; Butt 2011). Mothers living with HIV, therefore, the regardless of the parts they take in engaging health services during the best whether they are silent or not.

whether they are silent or not.

Unprofessional attitudes can happen in healthcare settings due to non-communication between the patient and health workers (Griffich, Almost Communication between the patient and health workers to separate the moral values that underpin their purspendicularly in care women living with HIV and the necessity to act professionally in care their work. In an emergency situation, such as the COVID-19 passion their work. In an emergency situation, such as the COVID-19 passion their work in an emergency situation, such as the COVID-19 passion their their work in an emergency situation, such as the COVID-19 passion their work in an emergency situation, such as the COVID-19 pandenuc may result in organizational ulance or salence that can be a threat to patients health, as seen in previous health the past (Henriksen and Dayton 2006).

One example of this silence comes again from Nur's story. A health some treated Nur's malnourished child decided to refer the child to the public treated Nur's malnourished child decided to refer the child to the public treated Nur's malnourished child decided to refer the child's HIV status and membration needed to be transferred because there was no doctor available to true manned to the transferred because there was no doctor available to true manned to the district of health workers. After a year, Oneng did access to her district of health workers. After a year, Oneng did access to her beauth care for her complications with support from NGO works, he was too lite and led to her death.

Another example of silence is seen in Widi's story. With also desire ma disclose her HIV status because if she tried to access care, she feared she may been denied the opportunity to deliver her baby in the hospital. The hispalls did not carry out the mandatory HIV test, which should have been par dispeblood testing before her delivery. Widi was placed in a no-win structure of the every woman living with HIV. Disclosing may lead to a negative reporteral receiving demeaning health services, but if they do not disclose their leads worsen and they risk further complications or even death. In this was talk ful silencing by mothers living with HIV during the COVID-19 parties be interpreted as a protest against the hopelessness experienced by wind accessing health services. First, the government failed to powide held and for these marginalized groups before and during the pandenne Scortle institutionalized discrimination in health settings, therefore health settings have an unprofessional attitude towards patients living with HIV ibot stands. Andajan, and Davies 2020. mah, Andajan, and Davies 2020). Third, women living with HIV 100 perceived barriers as a destinated perceived barriers as a destiny given to them by God (takife). In other was feel they do not deserve proper feel they do not deserve proper care and they must accept this as a way their sins in the hereafter (abbits of their sins in the hereafter (akhirat). Sadly, silencing may be associated at a silencing may be associated at the silence of mothers living with 1413. one of mothers living with HIV in surviving life with HIV (Dale #

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Conclusion

point the COVID-19 pandemic, there were overwhelming demands on workers halds review, which inevitably meant scarce mounts being shifted may from a being described less pressing medical conditions, including HIV This reallocaactually are all the considerable impacts on HIV-positive, program wheneve. The duty of female and COVID-19 treatment resulted in an intersection of negative factors, include to considerable impacts on women living with HIV, who already faced againment barriers to treatment. The culture surrounding HIV, and sexuality in goral is smaller to the Indonessan government's early response to COVID-19, in har being and communicating this issue started with, and to some degree, remains, one of clemial.

What lessons can be learned from this research? (are diagnoss and centing of Beth HIV and COVID-19 reflect institutional and cultural barriers that surround the transment of HIV in the era of COVID-19. They suggest an interplay of analquate communication and coordination between levels of government and the girms health services, relative avoidance of treating women living with HIV to healthcare providers, and a lack of standard operating procedures for HIV and COVID-19 patients. COVID-19 has highlighted these issues in Indonesia, offerme an opportunity to develop better treatment of HIV-positive women, as well as approing Indonesia's experience with meeting any fature outbreaks of currently acknown diseases (and many existing ones that also face social stigmas).

Acknowledgements

We are extremely grateful to the HIV-positive women who helped in in this study Think you to our research assistant, Nadilla Nusirwan, Happy Mira Jordanii, Anandu Eka Putri, Riska Isnami, S.Gz., Erni Wahyum, Sita Nariswari, and dr Chynta Rahma Vanvie. Also thank you for the research grant from Alumni Grant Scheme Round 2, Australian Awards for Indonesia, 2020–2021. Thank you Monash Unisensy and Sriwijava University for supporting this research.

Notes

All names used in this research are pseudonyms. Yn judi ini yang bikin aku sedikit, apo ye (Terisik). Sedikit bingung cak itu nab. Api yo tho cak its mah. Sampe sekarang pun dio kadang, ngapolah adek mit misusa ohat sens mak ye katomyo. Iyo karing ini yang bikin, yo sedikit terenyuh kan Jack yo iku kalo melah menangan pangangan pangan pangangan pangan pangangan pangangan pangangan pangangan pangangan pangangan pangan pangangan pangan pangan pangangan pangangan pangangan pangan pangangan pangangan pangan panga tudali garman kito, sudah garii rasab kito. Yo diteratto bae lah dulu. Yo cak mano jalan lahan kito, sudah garii rasab kito. Yo diteratto bae lah dulu. Yo cak mano, area Inhon kagek, ImyaAllah pesa ada jalan kan. Cak ins. Di ekulah disuruh namo, seco-tih-cim bada hayaAllah pesa ada jalan kan. Cak ins. Di ekulah disuruh namo suruh the city, hole kars, cak its kan. Idak. Athausdullilah, idak Kalo menung yang ita tuh.

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to a process of spiritual rebirth or becoming paraderos. Jack kalo kiso, agak mi many. Yo dao kan sekatang lagi sibuk pago ngorosa paraderos. Jack kalo kiso, agak mi many. Yo dio kan tekatang lagi sibuk sugo ngorang terlalu detail can minah ngoran din min agak can mino se agak kurang, kurang terlalu detail can minah ngoran dan minahanyo kayak, diperikan dada din tuh ugak cak mano ya igak kurang. da intilahnyo kayak, diperikan dado, da nah, jauh dio opohan kito cah jauh. Idak do intilahnyo kayak, diperikan dado, da nah, jauh dio opohan kito cah jauh. mah, jauh dio opohan kito rah jauh 1000 apek kito ganti obat. Cak an lag laba apo, idak. Denger belahan kito, yosudah apek kito ganti obat. Cak an lag laba apo, idak. Denger belahan kito jauh bour apo curhat dengan dokter ini kato iki. apo, schik. Denger helaban kitin yesses curhat dengan dokter ini kato iki. Eda raso kecewa, pidi ay ambihish buat apo curhat dengan dokter ini kato iki. Eda raso kecewa, pidi ay ambihish buat apo curhat dengan dokter ini kato iki. Eda raso kecewa, jadi ay antahin ban apan kemaren, suruh mangap (buka main) ha kan senep has kan seilahnyo cuma Irapan kemaren, surum ini bae, kumur-kumus mana bask-baok, munum ini baok, munum in senep has kan sedahnyo cuma trapina. manum ini bas, kumur-kumus basa, sariawan. Terus kate uanya bask-bask, manum ini bas, kumur-kumus banga basa nariawan. Terus kuto nanya basa ladi dak katek istilah manokan yang lam dak ladi dak ladi dak ladi dak katek istilah manokan yang lam dak ladi da Cak itu. Coli ukelan kato aku jagus yang ini bu, minum itu, manam itu lalak kan ibaratnyo. Obat mah yang bagus yang ini bu, minum itu, manam itu lalak kan ibaratnyo. Obat mah yang bagus yang ini bu, minum itu, manam itu lalak kan ibaratnyo. kan daratnyo. Obat man yang sagai kepa, mungkin sekitar semeter semete Iyodon, jiraknyo pake, satati. Hampir sehiruh sih. Tapi kalo yang di bagian magan jah lah kato dodok sekarang. Hampir sehiruh sih. Tapi kalo yang di bagian magan gate lab keto dodos sekarang, mano sali. Dak tau ngapo. Kalo di bagian anak-mak a door bearsk. Mereka tesep perikso, perikso dado, perikso apu, perikso mi itik ta parla aku saket ati lagi, kupikir kan talak ke lah sano lah.

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Without anti-retrovatal treatment, the risk of I HV transmission from infected metato their children is 15-30 percent during gestation or labor, and 15-20 percent during breasfeeding (Volume and Maran 2008). The World Health Organization pure figure higher at a 45 percent chance of transmission (World Health Organization 2015

Perawat menjelasken dokter spesials untuk merawat anak aku, lagi ado gawe bedan tidak biso datang ke rumah sakit. Jadi rumah sakit memutiskan umuk menjal me saya ke rumah sakit pemerintah (umum) jam 10 malam. Setelah tiba di rum 180 dokter menjelaskan status HIV anak saya (dengan berbisak).

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COVID-19. Surviving a Pandemic provides critical insights into survival strategies employed by communities and individuals around the world during the pandemic

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Drawing on the expertise of scholars from around the world, the work presented here represents a remarkable diversity and quality of impassioned scholarship on the impact of COVID-19 and is a timely and critical advance in knowledge related to the pandemic.

J. Michael Ryan is an award-wirning teacher who has held academic positions at top-ranked universities across five continents. He is currently Associate Professor of Sociology at Nazarbayev University (Kazakhstan) and has previously held academic positions in Egypx, Portugal, Ecuador, and the USA. Before returning to academia, Dr. Ryan worked as a research methodologist at the National Center for Health Statistics (which is part of the Centers for Disease Control and Prevention) in Washington. DC, where he led multiple projects aimed at improving national statistical survey methodology. He is the author (with Serena Nanda) of COVID-19- Social Inequalities and Human Possibilities (Routledge 2022) and (co-jeditor of more than 15 volumes including COVID-19- Global Pandemic, Societal Responses, Ideological Solutions (Routledge 2021), COVID-19- Social Consequences and Cultural Adaptations (Routledge 2021), and Core Concepts in Sociology (Wiley 2019). He is also the lounding editor of Routledge's The COVID-19 Pandemic Series.

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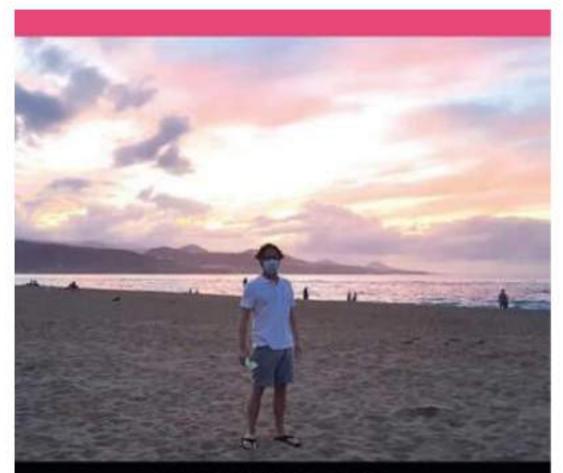
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Edited by J. Michael Ryan

THE COVID-10 PANDEAUC SERIES



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VIEW LESS

Abstract: Prior to the COVID-19 pandemic, available data suggests nearly three out of ten mothers in Indonesia were successfully managing their HIV (human immunodeficiency virus)

(UN AIDS 2020). These mothers were able to source required medications, and when pregnant, were able to access prevention of mother-to-child transmission services to decrease the chance of transmitting HIV to their babies. However, the COVID-19 pandemic affected the ability of mothers to access HIV care in two primary ways. First, many mothers living with HIV became fearful of going to hospital (for care or even to collect medicine) because hospitals became places where people became infected with COVID-19. Second, mothers were afraid of disclosing their HIV status when giving birth because hospitals were at capacity, and disclosing one's HIV status, even when in labour, could mean the hospital refused treatment due to the perceived added resources needed. Knowing this possibility, some mothers living with HIV delivered their babies in hospital without disclosing their HIV status. A culture of silence

pervades the intersection of HIV and COVID-19, and Indonesian society is yet to have an open discussion about the interplay between these two diseases.

This chapter explores the stories of three mothers living with HIV as they navigated Indonesia's COVID-19 pandemic. The chapter reveals that mothers failed regardless of the path they took: If they stayed away from medical care to avoid contracting COVID-19, they knew they could die; if they tried to access care and declared their HIV status, they might have been denied care; if they accessed care and did not declare their HIV status, they could not access the HIV treatment that kept them and their children alive. In addition, the stigma attached to HIV and the reduction of HIV tests availability during the pandemic resulted in many missed opportunities to diagnose HIV among pregnant women. While HIV and COVID-19 are different diseases, the silence surrounding both results in poor health outcomes for women.



Disclosing One's HIV Status During Indonesia's COVID-19 Pandemic

Challenges Faced by Mothers

Najmah 0000-0002-7370-9702, Kusnan 0000-0000-0002-7370-9702, Tom Graham Davies 0000-0001-5225-4051, and Sharyn Graham Davies 0000-0001-5348-4051

Introduction

My daughter, Via (living with HIV) (11 years old), I wants to be a police officer. She always mentions this ambition to her friends and teachers at school. But can she pursue this ambition? I am unsure (voice sobs). Via always asks me why she needs to take these medicines (anti-retroviral medicines, ARV). Her questions make me sad. However, I tell her it is our destiny; it is our fate (sudah nasib kito). We have to keep taking our ARV medicines, I tell her. I need to take mine too. I need to fight as I have six children. If I stop taking ARV medicines, I will pass away (potos nyawo). It would be a pity for my children. If

(Oneng, January 2021)

Oneng passed away from HIV complications (possibly COVID-19 related) in June 2021. As a widow, she left behind six children. She was the sole income earner, meaning that her children are now facing difficult financial hardship. When Oneng feelill, she knew she should go to the hospital for treatment, but she was too afraid to go. She believed that if she went to the hospital, she would contract COVID-19, and if she was hospitalized, she would be tested for COVID-19 and test positive. Oneng thus died at home, and the precise cause of death remains unknown.

Oneng's story of dying from HIV complications in the time of COVID-19 is sadly not exceptional in Indonesia. Widi, a pregnant woman living with HIV, shared a similar story. Like Oneng, Widi avoided visiting the hospital when she was ready to give birth for fear of contracting COVID-19. At any other time, Widi would have sought help from the prevention of mother-to-child transmission (PMTCT) services at her public hospital in the central city of Palembang. Widi knew that this service was the best way to avoid transmitting HIV to her unborn baby. Like Oneng, Widi believed that hospitals had the highest number of COVID-19 patients in South Sumatra. Widi thus gave birth to her baby at her local village hospital, and while she felt able to disclose her HIV status, the hospital did not offer PMTCT services.

Prior to COVID-19, both Oneng and Widi had for many years successfully managed their HIV using ARVs and accessed PMTCT services when delivering their bables. But the COVID-19 pandemic affected their desire to access such help. Women with HIV were often afraid to go to hospital because they knew that, as people with underlying health conditions, COVID-19 was a particular threat to their well-being. It was not just contracting COVID-19, however, that kept mothers living with HIV away from hospitals and thus access to ARV medications. These mothers were also afraid of disclosing their HIV status. With hospitals prioritizing COVID-19 patients, disclosing one's HIV status could mean one was turned away from the hospital without treatment. As such, some women living with HIV delivered their babies in hospital without disclosing their HIV status. They knew this would put themselves, their baby, and the medical staff at risk, but they saw no other option.

Parallels may be drawn between Oneng's and Widi's stories, as both highlight the cultural silence surrounding HIV in Indonesia and how HIV intersects with COVID-19. Both HIV and COVID-19 are veiled by a culture of denial, with governments, and even health officials, downplaying their respective dangers (Nanda and Ryan 2022). Sadly, this silence has resulted in increased suffering and preventable deaths. There is also a gendered aspect to this silence. For instance, mainstream narratives in Indonesia declare. that 'good' wives and mothers do not get infected with HIV. As such, disclosing one's HIV status classifies a woman ipso facto as a 'bad' woman (e.g., someone who has had high-risk sexual intercourse and/or intravenous drug use) (Najmah et al. 2020). This classification exacerbates the already difficult health and economic challenges experienced by women living with HIV. As such, some women 'choose' to stay silent about their HIV status when they try to access pregnancy care. The culture of silence also feeds into and exacerbates fears of COVID-19, which are then compounded by the ill-treatment by health service providers of women living with HIV. The women living with HIV we came to know during this research told us of their lives. Sadly, their stories include a great deal of suffering and of economic struggle to meet daily necessities, as well as the stigma of living with HIV, in a time of COVID-19. This chapter examines how inequalities in gender and health care intersect with a lack of support services for women living with HIV that exclude women from the help they need.

Within this analysis, we explore two key themes. The first theme examines how COVID-19 increases the risk of death from HIV in Indogesia. The second theme investigates how the silence surrounding HIV results in the ill-treatment of women living with HIV in health service settings. The methodology guiding the research was feminist-participatory action research. The facus of the research was marginalized women living with HIV in South Sumatra, Indonesia, and was conducted between December 2020 and August 2021.

Research Setting and Method

Our research site is located in Palembang, South Sumatra, Indonesia. Palembang is bordered by the Banyuasin Regency to the north, east, and west and Muara Enim and Ogan Ilir Regency to the south. Palembang's area is 40,000 km2, with a population of 1.7 million people in 2020 (Badan Pusat Statistik 2020). Palembang is divided into two main areas by the Musi River: Seberang Ilir and Seberang Ulu. The average monthly income of a Palembang worker is approximately Rp 1.2 million (\$85 US in 2022), with about 200,000 or 11 percent of the population living on less than half of that, Rp 480,000 (about \$35 US per month in April 2022) (CEIC 2019). While men and women over 15 years have similar access to education, unpaid domestic work in the home is still largely undertaken by women, with about 92 percent of women doing the majority of domestic work (Miranda 2011), a high rate by OECD (Organisation for Economic Co-operation and Development) standards.iii

Palembang has 147 clinics, hospitals, and public or community health centres. However, the ratio of health workers to population is low, at about 0.5 per 1000 population or about 2000 health workers for 1.7 million people. By way of comparison, the WHO recommends a threshold of 4.45 skilled health workers (physicians and nurses/midwives) per 1000 people in order to achieve universal health coverage (World Health Organization 2015). In terms of antenatal visits, the majority of women (about 90%) in 2020 made at least four visits. Contraceptive methods among married spouses are mainly progesterone injections, the pill, and implants (Gafar et al. 2020). In terms of HIV-related health services, in 2021, Palembang has four sexually transmitted infection (STI) clinics, 56 voluntary counselling and testing (VCT) clinics, 38 HIV care, support, and treatment (CST) local health clinics (puskesmas) and hospitals, one methodone clinic, and only two hospital-based HIV care and PMTCT services. Prior to COVID-19, antenatal HIV tests were provided in all 41 puskesmas in Palembang (Public Health Office of Palembang, 2021).

This research project used a feminist participatory action research (FPAR) framework devised by Patricia Maguire (1987). Maguire highlights the importance of building trust, creating meaningful participation for women throughout the research process, and ensuring outcomes that include a collective critical consciousness that challenges oppressive attigudes, beliefs, and practices that may be deeply embedded in society. We use FPAR to explore pregnant women living with HIV's experiences accessing healthcare services, including antenatal care during the COVID-19 pandemic.

In line with FPAR, we use methods devised by the women to encourage what Maguire refers to as 'deep voice' expression. We also employed observation, ethnography, online discussion gapups and face-to-face meetings, and diary notes, as a form of triangulation. The interviews explored the experi acces of 20 women living with HIV, who were either pregnant, or had been pregnant, or had a child born with HIV during the first year of the pandemic. The groups had an average age of 29, and their above-average monthly family income ranged between Rp 1,500,000 (\$100 US) to Rp 4,000,000 (\$280 US).

A Snapshot of HIV in Indonesia

People living with HIV are subject to significant obstacles and discrimination in Indonesia. According to the WHO, out of the present population of 270 million, there are currently over 670,000 people living with HIV, or approximately 0.2 percent (2)DS and HIV Data Hub in ASIA Pacific 2020), although this number may be grossly underreported. The United States Agency for International Development (USAID) suggests that only 44 percent of HIV cases are apported in Indonesia (USAID 2021). Two-thirds of the HIV population is male and one-third is female. The number of pregnant women with HIV increased by 25 percent from over 15,000 in 2012 to over 19,000 cases in 2016 (Ministry of Health 2018). There are approximately 220,000 AIDS orphans in Indonesia (AHF Indonesia 2016). Broadly, there is a poor level of information available to Indonesians about how HIV is transmitted and treated. The lack of accurate information is compounded by the almost complete absence of sex education in Indonesia, as many officials oppose its inclusion in school curricula. Condom use is low among sexually active people in Indonesia. Estimates suggest that less than 5 percent of married women use condoms and only 25 percent of unmarried male adolescents do (Putra et al. 2018).

The availability of anti-retroviral treatment is low, with only about 26 percent of people living with HIV (PLHIV) able to access it (UN AIDS 2020). There is considerable stigma and condemnation of sex outside marriage, resulting in higher rates of STD transmission (Wibawa 2019), including HIV. Same-sex relationships are generally met with public disapproval in Indonesia, meaning that LBTQI+ people face significant public and law-based discrimination, with gay clubs and health centres frequently raided by police (Human Rights Watch 2018; Yulius 2015). Similarly, people living with HIV are more likely to experience violence directed at them and have higher rates of suicide and other mental health issues (Breuer et al. 2011; Sherr et al. 2011). There is some positive news. Due to recent efforts to combat HIV, the reported number of new cases of HIV has declined from 38,000 in 2015 to about 28,000 in 2020 in Indonesia (UN AIDS 2020).

Living with HIV negatively intersects with actions taken by the Indonegan government to address COVID-19, examples of which are explored in the following stories of women living with HIV.

Indonesia's Response to COVID-19 (January 2020 to June 2021)

Figure 9.1 tracks changes in how the Indonesian government responded to the challenges presented by COVID-19, moving from a position of outright denial, through to large-scale social restrictions, overselling the role of vaccination, and finally, reducing COVID-19 prevention to the level of individual actions. With the benefit of hindsight, it is easy to be critical of the failures of the Indonesian government.

[Insert 15032-5591 - 009-Figure-001 Here]

Figure 9.1 Timeline of government responses to the COVID-19 pandemic

The Indonesian government's initial response to the COVID-19 pandemic was a lost opportunity to successfully reduce the impact of this deadly disease, particularly in light of its impacts on women living with HIV. Statements made by the Indonesian government initially denied the possibility that COVID-19 could exist at all in Indonesia. Following the first confirmed cases, the government's narrative then changed from denying the existence of the disease to downplaying the disease's lethality. Controversy surrounded the government with statements made by ministers and legislative members alike

vigorously understating the virus's potential impact. For example, in February 2020, the minister of transportation, Budi Karya, stated, "Indonesian people are immune to Corona because we like to eat 'nasi kucing' [a small portion of rice with anchovy, egg, fried fermented soya bean (tempeh), and other ingredients wrapped in banana leaves]" (Redaksi 2020). Ironically, he was then exposed to COVID-19 and treated twice for the virus (Sitorus 2020).

By April 2020, the Indonesian government accepted the reality of COVID-19 and introduced large-scale social restrictions along the lines of many other nations (Pembatasan social bersiala besar, PSBB). There were six types of activity restrictions. These included (1) studying and working outside of the home; (2) religious activities; (3) activities in public spaces; (4) social and cultural activities; (5) transportation; and (6) other activities, mainly related to defence and security.

The speed of communicating directives requiring public restriction also reflected the malaise of central government implementation. Policy communication between layers of government, from central to province and finally down to the city level, were sluggish. Despite modern, instantaneous communication technology, the timeframe between central government policy announcements and local government officials receiving policy directives could be measured in weeks. By this time, both the disease and the policies addressing its impact may well have moved on.

During one of these changes, at the beginning of June 2020, the Indonesian government introduced the phrase "the new normal era," which encapsulated the notion of accepting the inevitability of the disease and adapting to change by living with COVID-19 (adaptasi kebiasaan baru). At the time, cases of COVID-19 had increased significantly, and the economic impacts of social restrictions began to be felt at both the central government and individual levels (Breslin 2022).

The adoption of the new normal suggests that the central government came under significant economic pressure to favour less economically damaging policies, with the cost of health impacts being, once again, downplayed (Citra Rosa 2020). From August 2020, the government narrative changed again to dispensing information about COVID-19 vaccine trials, even though the Indonesian government was aware that vaccination would not, at that point, end the pandemic. Images of smiling health workers were shared on social media, suggesting a panacea for the COVID-19 pandemic (Najmah et al. 2021; Sanford et al. 2022). By May 2021, the government's narrative was modified again to encourage microscale public activity restriction (PPKM), particularly after numbers of COVID-19 cases of the Delta variant occurred, leading to a rise in COVID-19 cases in over 130 other countries (Chookajom et al. 2021). The Delta variant also led to a significant increase in COVID-19 cases in Indonesia (BBC News 2021). Prior to the Delta variant, daily reported cases ranged from between 5000 and 10,000. By the end of July 2021, the number of new cases reached 30,000 to 50,000 daily.

This approach returned to something similar to PSBB. Central government ministers directed governors and municipality leaders to mobilize actions at the individual level, including in schools, workplaces, restaurants, markets, and praying halls (Kompas 2021). However, the implementation of this policy was poorly managed and coordinated, and the focus was still an economic one, with the minister of home affairs being replaced by the minister of maritime and investment affairs.

Similarly, during the Eldiv celebration, the Islamic day that takes place at the end of the holy month of Ramadhan, an inconsistent and highly telling statement was made by Indonesian president Joko Widodo. Despite social distancing and physical movement restrictions, he encouraged the indonesian people to do 'pulang kampong,' meaning to break physical distancing restrictions and visit their hometowns during the long holiday. Similarly, the minister of tourism and creative economy, Sandiaga Uno, undermined his government's own goals of restricting movement by reopening popular tourism destinations such as Bali, and another minister allowed the entry of Chinese health workers into Indonesia (Najmah et al. 2021).

By July 2021, despite obvious evidence to the contrary, denial once again became the watchword by the minister of maritime and investment affairs, Luhut Binsar Pandjaitan, who confidently proclaimed that COVID-19 in Indonesia was now under control. However, a few days later, he made an about-face, informing the general public that the Delta variant could not be effectively dealt with (Anugerah 2021). These are just a few examples of the more glaring and inconstant messages proclaimed by high-ranking Indonesian officials. We now turn to the individual impacts of these policies.

A Battle Lost: Life and Death Among Women Living With HIV During COVID-19

The first author knew Oneng for the last three years of her life and witnessed the considerable effort it took for the took for the survive the death of her husband, raise six children, be a breadwinner, and access ARV therapy. She represented the concept of a traditional indonesian housewife or ibu rumah tangga.

During our interviews, Oneng spoke of the lack of support from health and nongovernmental organization (NGO) workers for her condition. In one instance, she expressed her frustration and anger when one NGO worker ignored her request for help to get ARV medication from the hospital. When her condition worsened, she sought a consultation during her monthly visit to the HIV centre in the public hospital. Her deteriorating condition proved extremely challenging for her as restrictions in health facilities during the pandemic led to the introduction of protocols that changed how doctors and patients interacted. The doctor she spoke to could not check her directly, kept a physical distance and only provided her with a prescription, and altered the combination of her ARVs to minimize their side effects. She added that some doctors who had previously treated her HIV were employed elsewhere, attending to COVID-19 patients, and were too busy to treat their regular patients. As a result, Oneng delayed her much-needed hospitalization and resorted to self-treatment by combining herbal medicines with her ARVs. After her condition worsened even more, Oneng decided to visit the emergency room in the public hospital. She revealed the following:

And right now, I feel sick because of increasing stomach acid. I was treated in an emergency room in a public hospital. Health workers provided quick treatment, therefore I was motivated to recover. Health workers knew I was living with HIV, and I had to undergo some procedures, including two scans in the emergency room. Then, during my hospitalization, I underwent two ultrasound checks. So many doctors cared for me, and I believe . . . that was the result of help from an HIV NGO who begged for me to be treated.

(Oneng's diary notes shared with the first author, April 2021)

Women living with HIV in this study shared with us the struggle to get HIV care. HIV service provision decreased during the pandemic, as medical resources were stretched. The already present alienation felt by women subject to HIV-related stigma was worsened by COVID-19 protocols such as physical distancing between patients living with HIV and doctors. In some instances, tables were used as barriers to minimize contact between HIV-positive women and health workers in VCT because of COVID-19

concerns. Before the pandemic, women living with HIV would normally consult doctors without any separation and would sit closely in a counselling room. Interestingly, physical separation was not carried out by doctors who had been well trained for HIV programs (Najmah observation during PhD fieldwork, 2017–2018). However, physical distancing became the norm during the pandemic (Romania 2022). With the shortage of health workers, well-trained HIV doctors who normally provided HIV therapy had to double up their roles as general practitioners treating COVID-19. Consequently, the limited access to HIV-related health specialists compounded the reluctance of women living with HIV to get health care, even when they were feeling extremely sick. Oneng spoke of her experiences.

The doctor who has a role in HIV treatment also has another role in mitigating COVID-19. Therefore, he was overworked and not able to give detailed help or provide consultation. There was no chest check or other direct physical check-ups. The doctor only listened to our symptoms and then changed my drug. That was all. When my mouth was full of scurvy, the doctor suggested gargling with water and salt, and there was no other suggestion, like what medicine I should take or other suggestions. I was disappointed and asked myself why I visited the HIV facilities. I sit at a distance of 1.5 meters from the doctor. However, in the paediatric room, there is no distance between the child living with HIV and the doctor; the doctors undertook regular check-ups for my child. I think it is better not to consult about my health condition, rather than my heart is broken.

(Oneng, a virtual interview)v

I never been asked by the doctor. The health worker who asked me was the pharmacist who provided our ARV medicine. How are you, mom? Do you have any symptoms? Do you feel sick? I can see some doctors, two to four young doctors, sit in the consultation room for HIV patients, but the doctors are [too] busy to discuss on their own. When I saw them, I said I did not have any symptoms, I only felt tired and got a headache. And I took my medicine and went home.

(Eda in a focus group discussion)

The last statement made by Oneng in April of 2021, two months before she died, is about health services and NGO participation when they finally enabled her to access health services. While the authors applaud her bravery, and despite her intensive treatment at the end of her life, we cannot help but think that her death might have been prevented had she been given a timelier intervention.

After Oneng's funeral, the first author visited Oneng's family and experienced first-hand how the impacts of scarce medical resources, due to COVID, can extend to wider familial networks. Out of Oneng's six children, Ona was the only one who took care of her mother in hospital, and she added how deeply distressing it was to see her mother in such a state and on so many medications. Had she been given the attention she needed, it might have been avoided.

Women living with HIV may suffer from HIV drug resistance as ARVs may not work well and lead to opportunistic infection, like toxoplasmosis or gastritis (Basavaraju 2021). As researchers, we directly experienced both the hopelessness experienced by affected individuals and its impact on their wider families. We use this to high gight the tension between the struggle to gain access to appropriate HIV care and the pain borne by women living with HIV caused by the retasking of medical professionals during the pandemic.

The prior statement highlights the double burden experienced by women living with HIV who have other underlying health conditions (opportunistic infection), when subject to the negative consequences of COVID-19 related policies. The combination of a weakened immune system along with the fear and uncertainty of becoming infected with COVID-19 from health facilities results in fewer women seeking treatment and, therefore, lower life expectancy, as well as increasing the risk of wider HIV transmission (May 2017).

Furthermore, the low economic status of women like Oneng is compounded by health disparities (Schultz 2022) such as the nonavailability of doctors for these groups (Chenneville et al. 2020). Worryingly, in some cases self-treatment becomes the only perceived option for those who are too poor or too afraid to visit their health service providers when they have HIV. These barriers lead to delayed care seeking and put women living with HIV at higher risk of death.

The Triple Bind of COVID-19 Restrictions

COVID-19 restrictions were performed as strategies to reduce the spread of COVID-19. Initially, the government restricted travel between regions. In addition, due to shortages of health workers, hospitals restricted health services to minimize COVID-19 transmission. Finally, social restrictions led to avoiding hospital visits due to misinformation (Ryan 2022) about COVID-19 testing or COVID misdiagnoses. Unfortunately, the triple bind of COVID-19 restrictions constitutes a missed opportunity to prevent HIV transmission among mothers and children, as many mothers living with HIV may not disclose their HIV status to services to get the proper care.

Widi (34-years-old from a low-income family, living in a village, four hours from Palembang) decided to disclose her HIV status to health services before, but not during, the pandemic. She worked in the health sector and was trained in providing peer support for women living with HIV. In her case, she had already given birth as a mother living with HIV and was experienced enough to prevent transmission to her first and second children by opting to deliver them by caesarean section in a public hospital in Palembang.

However, during the pandemic, she decided to deliver her child vaginally for her third pregnancy. She told us that every month her obstetrician checked her pregnancy, but in spite of her experience as an HIV advocate, she did not feel comfortable enough to disclose her HIV status, as she experienced discrimination by being denied treatment when she asked for a referral letter for her therapy. We use her case to highlight the difficulties women living with HIV experience during the simple act of asking for health treatment in Indonesia. For those women from low socioeconomic status groups, who lack the educational and cultural capital to articulate the need for treatment, the barrier is almost insurmountable.

Because of these barriers, Widi decided to risk transmitting HIV to her child in her local hospital. The discrimination she experienced was, however, not limited to her local doctor and the public health institution. After the delivery, her husband asked Widi to breastfeed her baby in the hospital, as he was afraid the staff and her mother-in-law would discover her HIV status.

COVID-19 also imposed a travel barrier, as Widi expressed that she feared breaking COVID-19 distance restrictions by accessing PMTCT HIV services in Palembang, a four-hour journey by car from where she lived. I was initially hesitant to have my child (during pandemic) because I was afraid that I might transmit HIV to my baby. I also had fears of COVID-19 and travel restrictions from my village to Palembang. You know the pandemic is a difficult time for us (including economic challenges). There is an 80% chancevi that my child would be infected with HIV. However, my husband supports me in treating our baby together if our baby gets HIV.

(Widi, virtual interview)

Based on a survey conducted by the Global Fund from April to September 2020 across 502 health facilities in 32 countries in Asia and Africa, including Indonesia, there are several key reasons why people have tended to avoid visiting health services during the COVID-19 pandemic. Figure 9.2 shows that the main reasons include fear, mistrust, and uncertainty about the possibility of getting infected with COVID-19 from health services, limited public transportation due to mobility restriction, and the order of staying thome from the government (Global Fund 2020). These perceived barriers were also found among the majority of women living with HIV in this study and often resulted in nondisclosure of HIV status in health settings if the mothers needed to visit health services to access health services.

In July 2020] Yes, I seek health services in a hospital, I do not disclose my HIV status. There is a strong stigma of being an HIV-positive mother, I cannot imagine disclosing my HIV status. I [really] do not want to open my HIV status. Do you know why? Laccess the third-class facilities (there are 5–8 patients in a room), and stigma is strong during the COVID-19 pandemic (every patient was suspected of having the virus). I was alone during my hospitalization, no companion (from family) was allowed. If I am open about my HIV status, people will not treat me (run from me); no one will take care of me, inject the medicine for me. In my observation, health workers are still afraid of HIV compared to COVID-19.

(Nika, an informal interview; read Nika's story in Inside Indonesia; Najmah et al. 2021)

Without proper sterilization and disinfectants, strict infection control, and HIV therapy, the intersected elements of these barriers lead to missed opportunities to prevent transmission to babies, but also to other health workers and other patients (Mbanya et al. 2010; Wyżgowski et al. 2016). The COVID-19 pandemic might also hinder ART continuation and PMTCT services access (Jiang et al. 2020). For instance, HIV testing fell 41 percent and PMTCT access to 20–40 percent between March and June 2020.

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Figure 9.2 Barriers to accessing HIV treatment during the COVID-19 pandemic (Source: Global Fund 2020)

The disruption to HIV prevention services during the COVID-19 pandemic, including HIV screening for pregnant women, means more mothers are at a higher risk of not knowing their HIV status and more babies are at risk of potentially becoming infected with HIV (Global Fund 2020; Jiang et al. 2020). However, the silence surrounding HIV in healthcare settings means midwives and obstetricians often do not talk about HIV to pregnant patients. Consequently, not all midwives and obstetricians recommend that pregnant women do an HIV test, thus reinforcing the stigma (Hopkyns and van den Hoven 2022; Mondal 2022). As a result, many women may know their HIV status only after their children suffered from opportunistic infections, including malnutrition, and were offered an HIV test in the late stage in hospital. Unfortunately, COVID-19 restrictions also affect the late diagnoses of their children's HIV status.

The impact of COVID-19 on diagnosis is reflected in Nur's story. In October 2020, Nur needed to treat her first daughter, Anti (18 months old), who became malnourished due to a medical condition. Despite being able to afford a private hospital, Nur was unable to access appropriate services for her daughter. Immediately, she was referred to a public hospital, as the doctor who specialized in her daughter's condition was unavailable because of the pandemic.

The attending nurse explained that the doctor who specialized in treating my daughter's condition had other work to do and could not treat my daughter. Therefore, the hospital decided to refer my daughter to the public hospital at 10 pm. After arriving in the emergency room in the public hospital, the doctor explained the HIV status of my daughter (in a low tone of voice).vii

(Nur, an informal interview, 2020)

After arriving at the public hospital, she recalled that a doctor called her into the emergency room. It was a crowded room, so the doctor disclosed to Nur that her child was living with HIV in a low tone of voice in the corner of the room. "I was shocked to learn that she was infected with HIV," Nur said.

Nur's child is a moving example of the late diagnosis of HIV. Though Nur accessed an obstetrician, an antenatal clinic, and a midwifery practice, she was not offered an HIV test at any time from 2017 to 2020. After experiencing three miscarriages, Nur was offered a complete blood test, which cost her Rp 3,000,000 (about US \$210 in 2022), but the test did not include HIV screening.

Free HIV testing for pregnant women is theoretically available in all public health services (puskesmas) in Palembang, however not all pregnant women visit puskesmas for their agreeatal check. About 55 percent of all mothers go to private midwives (Ministry of Health 2013), who do not offer onsite HIV testing (Wulandari et al. 2019). In short, it took the length of her pregnancy and the child's current age, nearly one and a half years, for the Indonesian health system to recognize the HIV status of a child born to a mother living with HIV. Nur's story also reveals the multifaceted barriers to accessing HIV treatment during the pandemic even after her child has been confirmed as living with HIV.

Health workers are also reluctant to discuss HIV because a stigma may be attached to their institution as a whole. Health workers may attempt to protect the 'good name' of their hospital by diverting patients living with HIV to another specialist or hospital (Ha et al. 2013; Najmah 2019). Had Indonesia instituted a program to better educate healthcare workers and work towards improved coordination between healthcare providers in the area of HIV, these issues and the suffering they cause may well have been avoided, or at least lessened (Knight and Bleckner 2022).

The Silence Surrounding HIV Combines With the Silence Surrounding COVID-19

While in certain situations silence can be an effective strategy, at other times it can lead to suffering and death. One of the most interesting findings from this study is that there is a link between the silence surrounding HIV and the silence surrounding COVID-19. There are three intersecting elements to silencing; first: silencing and shame; second: silencing and morality; third: silencing and religious practices. Unfortunately, giese silences contribute to delays in health-seeking behaviour, nondisclosure of HIV status by mothers living with HIV, and the concealment of HIV status by patients in health treatment settings.

The notion of shame is a key aspect of Indonesian and Muslim culture. Muslim women are in general taught to have a sense of shame, and being modest and shy is a part of the Muslim faith (iman). In this study, unfortunately, shame prevented many of our respondents from disclosing their HIV status and accessing health services and led to psychological difficulties. At the individual level, women living with HIV in Indonesian society may feel ashamed, dirty, and not respected or needed, and at the community level, HIV is often seen as something people contract as punishment for acting immorally (DeWees and Miller 2022). Therefore, silence is one means to avoid feeling the shame of being exposed to negative public attitudes, or silence is deployed when accessing much-needed health services, particularly with the constraints imposed on health workers during the COVID-19 pandemic where they may not have the resources to help PLHIV. Interestingly, staying silent may be interpreted as acceptance of the unfairness of health services (Wong-Padoongpat and Barrita 2022) and as a form of destiny or takdir, thus undermining public demand for improvements in treating HIV.

Shame is also a moral value and is institutionalized in health services in Indonesia (Bennett 2016; Butt 2011). Mothers living with HIV, therefore, may lose regardless of the path they take in engaging health services during the pandemic, whether they are silent or not.

Unprofessional attitudes can happen in healthcare settings due to non-transparent communication between the patient and health workers (Griffiths et al. 2022). This lack of transparency is exacerbated by the inability of some health workers to separate the moral values that underpin their perspective about women living with HIV and the necessity to act professionally in carrying out their work. In an emergency situation, such as the COVID-19 pandemic, maintaining health services for these marginalized groups does not occur. Therefore, the COVID-19 pandemic may result in organizational silence or systematized silence that can be a threat to patients' health, as seen in previous health crises in the past (Henriksen and Dayton 2006).

One example of this silence comes again from Nur's story. A health worker who treated Nur's malnourished child decided to refer the child to the public hospital. The health worker kept silent about the child's HIV status and merely said the child needed to be transferred because there was no doctor available to treat malnutrition. Oneng also then stayed silent about her own worsening health condition for a year due to her distrust of health workers. After a year, Oneng did access comprehensive health care for her complications with support from NGO workers, but it was too late and led to her death.

Another example of silence is seen in Widi's story. Widi also decided not to disclose her HIV status because if she tried to access care, she feared she might have been denied the opportunity to deliver her baby in the hospital. The hospital also did not carry out the mandatory HIV test, which should have been part of regular blood testing before her delivery. Widi was placed in a no-win situation, just like every woman living with HIV. Disclosing may lead to a negative response such as receiving demeaning health services, but if they do not disclose, their health will gorsen and they risk further complications or even death. In this way, purposeful silencing by mothers living with HIV during the COVID-19 pandemic may be interpreted as a protest against the hopelessness experienced by women when accessing health services. First, the government failed to provide health services for these marginalized groups before and during the pandemic. Second, there is institutionalized discrimination in health settings, therefore health workers often have an unprofessional attitude towards patients living with HIV (Butt 2011; Najmah et al. 2020). Third, women living with HIV may assume the perceived barriers as a destiny given to them by God (takdir). In other words, they feel they do not deserve proper care and

they must accept this as a way to reduce their sins in the hereafter (akhirat). Sadly, silencing may be associated with lower resilience of mothers living with HIV in surviving life with HIV (Dale et al. 2014). Unfortunately, the national health system is not protecting patients' rights to care, particularly during the COVID-19 pandemic.

Conclusion

During the COVID-19 pandemic, there were overwhelming demands on workers in health services, which inevitably meant scarce resources being shifted away from socially designated less pressing medical conditions, including HIV. This reallocation resulted in considerable impacts on HIV-positive, pregnant women. The shift to a focus on COVID-19 treatment resulted in an intersection of negative factors, leading to considerable impacts on women living with HIV, who already faced significant barriers to treatment. The culture surrounding HIV, and sexuality in general, is similar to the Indonesian government's early response to COVID-19, in that facing and communicating this issue started with, and to some degree, remains, one of denial.

What lessons can be learned from this research? Late diagnosis and testing of both HIV and COVID-19 reflect institutional and cultural barriers that surround the treatment of HIV in the era of COVID-19. They suggest an interplay of inadequate communication and coordination between levels of government and the relevant health services, relative avoidance of treating women living with HIV by healthcare providers, and a lack of standard operating procedures for HIV and COVID-19 patients. COVID-19 has highlighted these issues in Indonesia, offering an opportunity to develop better treatment of HIV-positive women, as well as improving Indonesia's experience with meeting any future outbreaks of currently unknown diseases (and many existing ones that also face social stigmas).

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All names used in this research are pseudonyms.

- Yo jadi itu yang bikin aku sedikit, apo ye (Terisak). Sedikit bingung cak itu nah. Apo yo biso cak itu nah. Sampe sekarang pun dio kadang, ngapolah adek nih minum obat terus mak ye katonyo. Iyo kadang itu yang bikin, yo sedikit terenyuh kan. Jadi yo aku kalo sudah garisan kito, sudah garis nasib kito. Yo diterimo bae lah dulu. Yo cak mano jalan Tuhan kagek. InsyaAllah pasti ado jalan kan. Cak itu. Di sekolah disuruh namo, teros cito-cito, hobi kan, cak itu kan. Idak. Alhamdulillah. idak Kalo memang yang itu tuh aku. Yo aku fokusken lah dulu, kagek lebeh parah. Aku punyo anak 6 ikok nak diperjuangke galo ini. Kalo potos, atau potos pulok nyawo kasian mereka.
- More information can be found here: Miranda, V. (2011), "Cooking, Caring and Volunteering: Unpaid Work Around the World," OECD Social, Employment and Migration Working Papers, No. 116, OECD Publishing. doi: 10.1787/5kghrjm8s142-en.
- Eid ul-Fitr, also called Hari Raya Puasa or Hari Raya Aidilfitri in Southeast Asia, is the first day of Shawwal in Islamic calendar. It is celebrated as Lebaran in Indonesia. It refers to a process of spiritual rebirth or becoming pious again.
- Yo dio kan sekarang lagi sibuk jugo ngorosi pandemi. Jadi kalo kito, agak ini mungkin, dio tuh agak cak mano ye agak kurang, kurang terlalu detail cak itunah ngoros cak itu nah. jauh dio ngobati kito tuh jauh. Idak do istilahnyo kayak, diperikso dado, diperikso apo, idak. Denger keluhan kito, yosudah agek kito ganti obat. Cak itu bae. Jadi aku raso kecewa, jadi ay sudahlah buat apo curhat dengan dokter ini kato aku. Kalo buat senep bae kan istilahnyo cuma. Itupun kemaren, suruh mangap (buka mulut) bae karena

sariawan. Terus kito nanyo baek-baek, minum ini bae, kumur-kumur banyu garem. Cak itu. Ooh okelah kato aku. Jadi dak katek istilah masokan yang laen cak itu nah kan ibaratnyo. Obat mah yang bagus yang ini bu, minum ini, minum ini. Idak. Katek. Iyoooo, jaraknyo pake, sudah dio dibalik meja, mungkin sekitar semeter semeter setengah lah kito dodok sekarang. Hampir seluruh sih. Tapi kalo yang di bagian anakanak, ibaratnyo idak do terlalu cak mano sih. Dak tau ngapo. Kalo di bagian anak-anak, idak dooo bejarak. Mereka tetep perikso, perikso dado, perikso apo, perikso ini, idak. Dari pada aku saket ati lagi, kupikir kan.talak ke lah sano lah.

Without anti-retroviral treatment, the risk of HIV transmission from infected mothers to their children is 15–30 percent during gestation or labor, and 15–20 percent during breastfeeding (Volmink and Marais 2008). The World Health Organization puts the figure higher at a 45 percent chance of transmission (World Health Organization 2015).

vii Perawat menjelasken dokter spesialis untuk merawat anak aku, lagi ado gawe (kerjaan) dan tidak biso datang ke rumah sakit. Jadi rumah sakit memutuskan untuk merujuk anak saya ke rumah sakit pemerintah (umum) jam 10 malam. Setelah tiba di ruang UGD, dokter menjelaskan status HIV anak saya (dengan berbisik).

Disclosing One's HIV Status During Indonesia's COVID-19 Pandemic Challenges Faced by Mothers

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