

# 'It's better to treat a COVID patient than a HIV patient': using feminist participatory research to assess women's challenges to access HIV care in Indonesia during the COVID-19 pandemic

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

## Abstract

**Background:** Women living with HIV in Indonesia encounter challenging obstacles to healthcare, which is exacerbated by COVID-19. Access is difficult as there are limited numbers of poorly supported healthcare providers. Women also face significant stigma when disclosing their HIV-status.

**Objectives:** Our main purpose is to give a voice to disempowered women living with HIV, by normalising the discussion of HIV, to empower health professionals to better understand the issues faced by women living with HIV, and develop improved treatment practices.

**Design:** Our project was guided by a Feminist Participatory Action Research (FPAR) framework. FPAR refers to 'a participatory and action-oriented approach to research that centres gender and women's experiences both theoretically and practically'. It creates meaningful participation for women throughout the research process, ensuring a collective critical consciousness that challenges oppressive attitudes, beliefs, and practices that may be deeply embedded in society.

**Method:** Purposive sampling and a thematic analysis was applied to focus group discussions with 20 women living with HIV and 20 women without HIV in Palembang, South Sumatra.

**Results:** When women living with HIV face a difficult decision, do they disclose their status knowing that they may face stigma and even a refusal to be treated; or do they conceal their status and face not receiving the right care? In this article, we explore the stories of women living with HIV as they seek medical treatment during the COVID-19 pandemic. We show that there is no optimal solution for women as they lose whether they disclose their HIV status or not.

**Conclusion:** Women's stories around HIV and COVID-19 intersect with conditions such as poverty and discrimination, as well as embedded gender systems, creating overlapping barriers to treatment. Government must challenge this culture by introducing a comprehensive sex and HIV education programme. This would normalise discussions of HIV-related topics, leading to improved health outcomes.

**Keywords:** COVID-19 pandemic, health services, women living with HIV, Indonesia, mothers

Received: 22 July 2021; revised manuscript accepted: 15 November 2021.

*Ther Adv Infectious Dis*

2021, Vol. 8: 1–14

DOI: 10.1177/  
204993612111064191

© The Author(s), 2021.  
Article reuse guidelines:  
[sagepub.com/journals-](https://sagepub.com/journals-permissions)  
permissions

Correspondence to:  
**Najmah Najmah**  
Public Health Faculty,  
University of Sriwijaya,  
JL. Raya Palembang-  
Prabumulih KM 32  
Indralaya, Ogan Ilir,  
Sumatera Selatan,  
Palembang 30662,  
Indonesia.  
[najem240783@gmail.com](mailto:najem240783@gmail.com)

**Sharyn Graham Davies**  
**Tom Graham Davies**  
Monash University,  
Clayton, VIC, Australia

**Kusnan Kusnan**  
INCEIF, Kuala Lumpur,  
Malaysia

## Introduction

Indonesia's COVID-19 pandemic has thus created barriers for women living with HIV in their efforts to access health services. Research on the experiences of women living with HIV during the COVID-19 pandemic is still limited, particularly in relation to Indonesia.<sup>1–3</sup> This article will explore two main themes that arose through our research. Theme one explores the perception of stigma experienced by women living with HIV and mothers without HIV. Theme two relates to exploring the experiences of women living with HIV when they try to access healthcare services during the ongoing COVID-19 pandemic.

For the second theme, we share three stories to show how COVID-19 has exacerbated the difficulties of accessing HIV care in pandemic times. Our first story tells of how Yana declared her HIV status to healthcare workers and was subsequently treated with discrimination. In our second story, we tell of how Nika decided not to disclose her HIV status when she was diagnosed with COVID-19 in the hopes that she would receive efficient and respectful healthcare. The third story, Tika and Nur, tell of how mothers with HIV fight against their self-stigma of HIV as well as fears of contracting COVID-19, the COVID-19 test itself, and to access the right healthcare treatment for themselves and their children, who are also living with HIV.

Indonesia has provided opportunities for women living with HIV to access health services under the National Health Insurance Programme.<sup>2</sup> However, while Prevention of Mother to Child Transmission (PMTCT) of HIV services and other services might be available, the stigma associated with accessing such services prevents many women from accessing help.<sup>2,6</sup>

Women with HIV are condemned as 'unfaithful' wives and are assumed to have had sex outside marriage, committed a sin, or be working as a sex worker. These beliefs have a strong, negative emotional impact, causing women to feel dirty, unworthy, or shameful, despite the fact that they may not have been involved in any of these behaviours. Evidence suggests that most women are infected with HIV by their husbands<sup>4,5</sup> (Anindita et al., 2013; Rahmalia et al., 2015)<sup>7,8</sup>. Despite this, women who disclose their HIV status face discrimination in health services, including denial

of confidentiality or privacy.<sup>2,4,5</sup> This is compounded by a fear of HIV held by many healthcare workers who experience difficulty in discussing HIV in antenatal services, or treating women living with HIV.<sup>6</sup>

During the ongoing COVID-19 pandemic, women living with HIV face an incredibly difficult time due to health inequalities.<sup>9–11</sup> If they disclose their HIV status to healthcare workers, they are likely to be refused care for two reasons: (1) healthcare workers are worried they and others will contract HIV and (2) with healthcare resources stretched beyond capacity, women living with HIV are seen as a low priority. Women know these outcomes and sometimes feel they have no choice but to hide their HIV status.

In August 2021, Nika, a mother of three children lost her battle with HIV. While Nika had been successfully managing her, and her children's HIV, the COVID-19 pandemic changed this. Previously, Nika had been able to prevent HIV to her child by accessing Prevention of Mother-to-child of HIV services. However, the pandemic diverted health resources away from HIV to COVID-19. Furthermore, it was rumoured that if you went to the hospital, you would contract COVID-19. Nika was thus too afraid to go to the hospital until her condition worsened. Sadly, by the time she was admitted, it was too late to save her life. Nika's story is just one of four stories we share in this article about the impact of the COVID-19 pandemic on HIV healthcare in Indonesia.

## Research method

The methods utilised in this project comprised of a series of focus group discussions (FGDs), and go-along (informal) interviews. To pre-test our research, we carried out a pilot project with five women in order to further refine thematic nodes, identify any issues encountered by the researchers, as well as practising a consistent interview schedule.

We further divided the groups included into (1) HIV status; (2) work status (a housewife only or a working mother); (3) the availability for face-to-face or virtual meetings. Each meeting was approximately 30–60 minutes, and there were between two and five follow-up meetings.

Digital audio recorders are used to collect all data and field notes were also recorded. All participants gave verbal or written informed consent for inclusion into the study, including the publication of this material. Only participants were present during the data collection phases. Transcripts were not returned to participants, and this was made clear during initial rapport building exercise. The logistics of this were too difficult, and low literacy skills meant more suitable ways of follow-up were preferred (e.g. post-interview and social media chats). For privacy reasons, all names are pseudonyms.

FGDs are particularly useful in gaining participant ideas and aspirations that might not have been accessible without group interaction.<sup>12</sup> Interviews were undertaken in some cases where a participant's preference over a group discussion was held in outdoor areas, such as a restaurant, visiting a house, and wearing masks.<sup>13</sup> In addition, participatory visual methods were used during a series of FGDs and interviews. Participatory visual methods are considered modes of inquiry, production, and representation in the co-creation of knowledge (Figure 2).<sup>14</sup> Alternatively, virtual FGD, interviews, and participatory visual methods were chosen if there was COVID-19 restriction, and the participants chose to do it.

Feminist Participatory Action Research (FPAR)<sup>15,16</sup> enabled the first and second author to work closely together with women. In particular, we worked with women of reproductive age because this is a demographic where we have particular expertise. Moreover, we focused on women from marginalised groups, such as women living with HIV and women from low- to middle-income families. This article applies FPAR to explore the diverse experiences of women living with HIV accessing healthcare services, including antenatal care, PMTCT services, and other health services.

The first author is an epidemiologist and a public health lecturer at a public university in Indonesia and graduated with a PhD from Auckland University of Technology in New Zealand. The second author is an anthropologist and has worked on research projects in Indonesia for over 15 years. The second author was born in Australia and has had over 15 years experience in a variety

of research projects in Indonesia and speaks Indonesian fluently.

Najmah and the third author worked together in data collection in the field and the third and fourth authors contributed to research by way of external evaluation and data analysis. All three authors communicate fluently in Bahasa Indonesia and have a good grasp of Indonesian culture, political, and social contexts. Both first and second authors identify as cis-gender women, the third author focuses on Islamic studies and the fourth author as a fiction book writer and sociologist.

### *Participant selection*

The participants were recruited purposively from Palembang, South Sumatra, Indonesia. There are two groups of women in this study: (1) 20 mothers living with HIV and (2) 20 women who were pregnant or had been pregnant during the COVID-19 pandemic and have experienced stigma while being tested for COVID-19 (Figure 1). An advertisement was sent *via* word of mouth and private message to women the first author knew who were living with HIV. The first author developed a close relationship with 15 women living with HIV during her PhD research. In addition, two non-governmental organization (NGO) workers in the HIV field helped to disseminate the advertisement to their networks. For the second group, pregnant mothers during the pandemic, two methods of recruitment were used (1) by word of mouth to women in the first author's neighbourhood and (2) through the first author's peers in her workplace. During the process of rapport building, the researchers identified their reasons for interest in this topic and openly disclosed their intentions regarding the research.

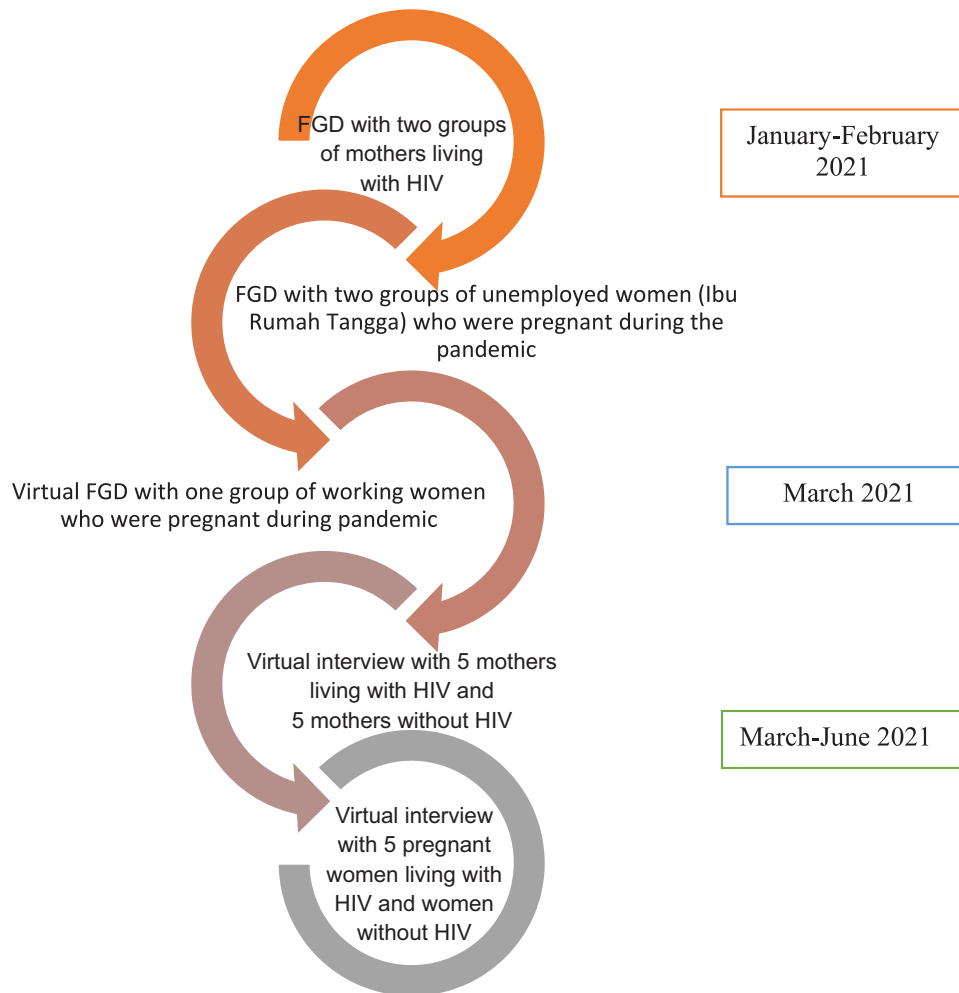
The inclusion criteria of both groups were (1) of reproductive age; (2) living in Palembang, South Sumatra; (3) having children or were pregnant during the pandemic, and (4) available to join a series of FGDs or interviews, face-to-face or virtual meetings on social media.

This article focuses on four narratives of 20 women living with HIV; a widow with three children, one pregnant woman living with HIV, and two mothers with HIV and whose children have

**Table 1.** Respondent's characteristics: Women living with HIV.

Name	Age	Marital status and owning house	Disclosure of HIV status			Experience of stigma and discrimination		
			Family (with who)	Neighbours	Healthworkers	Family	Neighbours	Health workers
1. Vela	25	Married Contracted house	Sister and husband	No	No	No	No	Yes
2. Widi	34	Second married	Second husband	No	No	No	No	Yes
3. Yana	25	Married Contracted house	Husband and sister	No	Yes	No	No	Yes
4. Nur	36	Married Parent's house	Husband and husband's family	Yes	No	No	No	No
5. Ika	36	Widow Owning house	Mother, sister, and brothers	No	No	No	No	Yes
6. Endah	49	Widow Parent's house	Family	No	Yes	No	No	No
7. Mila	41	Widow Parent's house	Parents and siblings	No	No	Yes	No	Yes
8. Viyah	40	Second married Owning house	Husband's family	No	No	No	No	No
9. Oneng	44	Widow Parent's house	Family	No	Yes	No	No	Yes
10. Nika	33	Divorce Parent's house	Family	Yes	Yes	No	Yes	Yes
11. Tiki	33	Married Owning house	Family	No	No	No	No	Yes
12. Rini	40	Widow Owning house	Nuclear family	No	No	No	No	-
13. Mawar	44	Widow Owning house	Nuclear family	No	No	No	No	Yes
14. Xani	35	Married Owning house	Family	No	No	No	No	Yes
15. Mona	33	Second married Contracted house	Nuclear family	No	No	Yes	No	No
16. Putri	38	Married Owning house	Husband	No	No	No	No	Yes
17. Maya	36	Second married Contracted house	Parent and husband	No	No	No	No	No
18. Mano	38	Married Parent's house	Husband	No	No	No	No	Yes
19. Bunga	33	Second married Owning house	Sister and husband	No	No	No	No	Yes
20. Mulan	31	Second married Contracted house	Second husband	No	No	No	No	No

HIV, human immunodeficiency virus.



**Figure 1.** Data collection cycle.

HIV (Table 1). The researches were conducted between December 2020 and August 2021.

### *Data analysis*

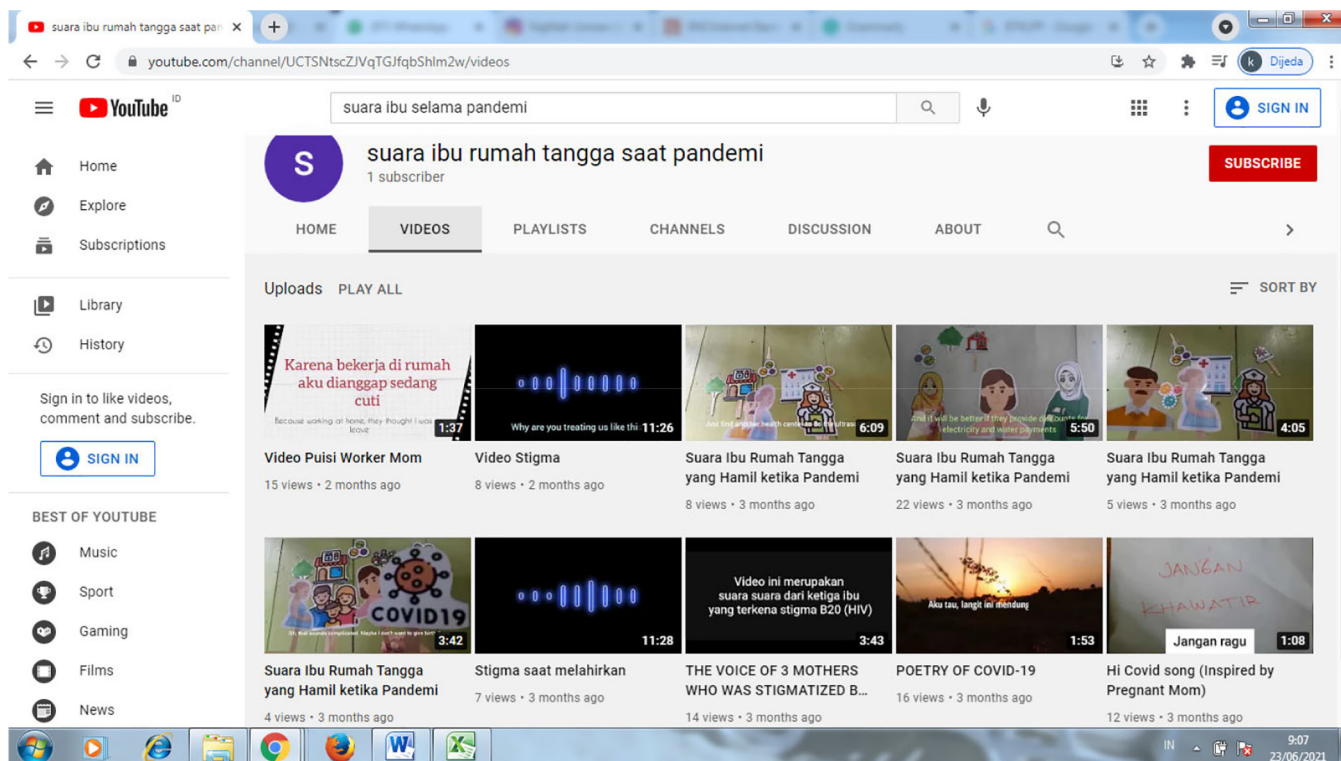
Narratives from interviews, group discussions, and visual outcomes were transcribed verbatim in Bahasa, Indonesia. Field notes were recorded in both Bahasa Indonesia and English and were sent daily during fieldwork to the second author. The interpretations of the women's voices and presentations were coded in their original language.<sup>17</sup> Regular chatting through private social media was conducted between the authors to discuss emerging themes, categorisation, and links between codes and meanings, enhance data interpretation, and ensure consistency. Both authors developed

themes from the coding before translating relevant quotes into English.

Thematic analysis was performed by applying the steps of Coding set out by Saldana<sup>17</sup> across different themes of HIV-related stigma, and discrimination of the women's experience during the COVID-19 pandemic. Three main thematic nodes emerged around the experiences of women living with HIV during the pandemic:

1. HIV-related stigma and discrimination.
2. Disclosure or non-disclosure of HIV status in health settings.
3. Fighting HIV stigma and discrimination: women's resilience in dealing HIV discrimination.





**Figure 2.** Visual outcomes of participants' action during research process.

Link: <https://www.youtube.com/channel/UCTSNtscZJVqTGFqjShlm2w/videos>.

Some of these visual outcomes, poems, video, song lyrics, and drama were published on the YouTube with the participants' permission. These visual outcomes were produced in the fourth or fifth meetings with participants. These visual outcomes helped both researchers to analyse the voices of women living with HIV together.



**Figure 3.** The label on women living with HIV (Najmah's documentation from the first group of mothers living with HIV).



**Figure 4.** HIV and COVID-19-related stigma intersecting for mothers living with HIV from themselves (*diri sendiri*), family (*keluarga*), neighbour (*tetangga*), society (*masyarakat*), health (*tenaga kesehatan*), and friends (*teman*). [Najmah's documentation from the second group of mother living with HIV].  
Link video: <https://www.youtube.com/watch?v=MvuVKfgRvhw>

### Respondent's characteristics: women living with HIV

In total, 20 women living with HIV and 20 pregnant women without HIV, during the pandemic contributed to this study. The women living with HIV were aged between 21 and 49 years. Six were widowed, one was divorced and 14 were married. Among women without HIV, 11 identified themselves as a housewife or *ibu rumah tangga*, and 9 of them were employed. Education levels ranged from Junior high school to post-graduate. The average family income was between Rp 1.500.000 (US \$105 to RP 5.000.000 monthly (US \$350) (as at 4/11/2021).

### Disclosing HIV status and COVID testing

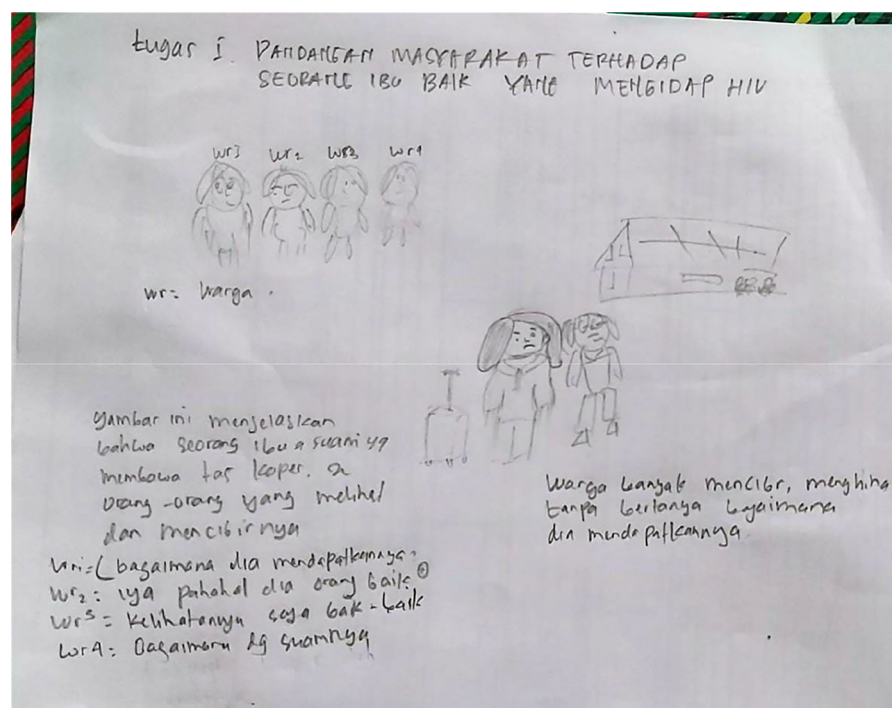
The majority of the 20 women living with HIV disclosed their HIV status to their families, including their parents and siblings. However, only four of the women disclosed their HIV status to health workers in non-HIV-health centres (such as a VCT centre), either in private practice or at the public health centre (*puskesmas*). Of the four who disclosed their HIV status, they did so

to get antiretroviral (ARV) medicine or give birth to their baby in PMTCT services. All 20 did not disclose their positive HIV status to their neighbours.

Only 10 women accessed a COVID-19 test out of 23 pregnant women during the pandemic as they delivered their babies or was hospitalised. Other participants who delivered in a private midwifery practice or obstetrician clinic generally were not offered a COVID-19 test. Among the non-HIV group, only 5 out of 20 women who were tested with HIV, nine were tested for COVID-19 when they accessed antenatal care in *puskesmas* or hospital.

### HIV-related stigma and discrimination

During the first year of the COVID-19 pandemic in Indonesia, in 2020, we found that stigma surrounding HIV increased significantly for women who sought health services during delivery or for therapy for other diseases. We define HIV-related stigma as negative beliefs, feelings, and attitudes experienced by people impacted by HIV. In the



**Figure 5.** Perception of a good mothers and wives living with HIV (Najmah documentation, drawing by Rima, mother with three kids, non-HIV).

Indonesian context, stigma can be interpreted as shame or *malu*. Mothers living with HIV defined stigma as meaning bullying (*ngatoi*), insulting (*menghina*), isolating (*mengucilkan*), and being fearful (*takut*) (Figure 4).

When faced with the decision to disclose or not to disclose, we found that women are negatively impacted either way. If they decided not to disclose their HIV status, they risk not receiving appropriate treatment for their HIV. If they do disclose their HIV status, medical professionals might refuse treatment for fear of contracting HIV.

Stigma extends to a broad range of potentially effected people. It includes not only people living with HIV but also members of high-risk groups such as sex workers, gay men, intravenous drug users, and also to those without HIV, people who live with them.

Stigma is also extended to married women who have been infected with HIV by their husbands.

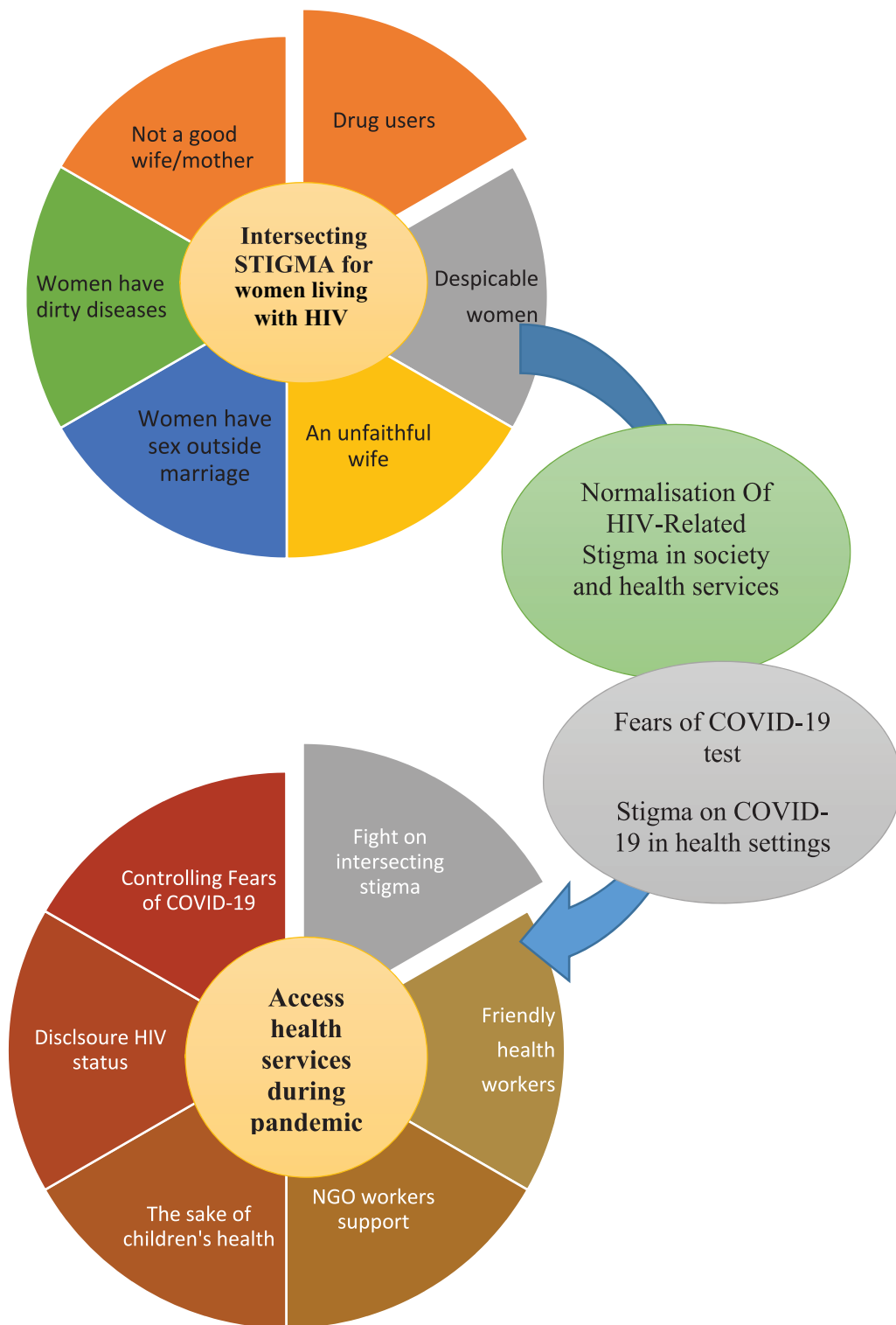
Our research revealed many stigmatised perceptions about married women living with HIV. All

of which were pejorative. Stigmatised perceptions begin with the false belief that it is not possible for good wives and mothers to contract HIV. Therefore, women living with HIV have *penyakit kotor* (dirty diseases). A corollary of this is that it is also considered a disease women get if they have sex outside marriage and change partners frequently (*gonta ganti pasangan*) and so are considered despicable women (*perempuan hina*) (Figure 3).

Sadly these beliefs are so widespread in the community, it is not uncommon for them to be expressed in public health settings.<sup>3</sup> On top of dealing with the often-traumatizing diagnosis, the impact of this stigma are feelings of deep hurt and isolation, as they felt they were good mothers (*perempuan berakhlak baik*). Sadly, the women who disclosed their HIV status to their family may also be subjected to discrimination by others towards their own children (Figure 4).

My children felt the same [stigma] though they are free of HIV. Stigma was hurtful not only for me but also for my children. Stigma was very painful for my children. We lived separately from our parent's





**Figure 6.** Resilience in fighting HIV and COVID-19 stigma during pandemic (developed by Najmah).

house, were mocked, insulted. It hurts a lot (Mila, a mother living with HIV, and widow with three children).

When we asked what were her perceptions of HIV were, one pregnant woman without HIV answered 'HIV is a dirty disease' (*penyakit kotor*). Another participant drew the picture in Figure 5 and added the explanation of the picture that.

We know there are other risk factors to get infected with HIV, such as a good woman may access beauty therapy where they use non-sterile equipment. However, the negative stigma was always there, before women with HIV explain about her experience. HIV-positive mothers may look like a good and pious mother, the reality she may not be (Rima, a working woman, free of HIV).

This dominant cultural belief contributes to the reluctance of pregnant women in the general population to seek an HIV test, or for health workers to offer HIV tests to their patients. Widi, an experienced healthcare worker, expressed the belief that a good mother should be confident that her husband is a good husband and expressed her opinion about HIV:

If we are confident with our husband, there is no health problem, I trust my husband. In fact, I am grateful if no one offer me HIV test. If I was offered the test, I will refuse to do it. (Widi, a working woman, free of HIV)

Widi also stated that stigma is also extended to people employed by HIV service providers.

HIV is still considered as a disgrace. If a clinic or hospital offers [an] HIV test, patients might run away, mightn't they? Women may think that health workers want to make them shame in front of others. (*Na maluken aku nian*)

Thus, we conclude that the stigma related to HIV is internalised by the women, society, and healthcare workers, leading to its own perpetuation. Although stigma relating to COVID-19 does not have the moral judgement attached to it, our study highlights that women living with HIV suffer from a double burden of stigma when they try to access healthcare during this pandemic. For instance, Nika was treated in isolation for

COVID-19 due to her severe cough, and Yuni was judged to be COVID-19 positive. Yuni always complains about unfair treatment for her baby during her delivery, though her COVID-19 showed negative.

*Yana's story: 'it is better to treat Covid-19 patients than an HIV-positive patient'*

In the first year of the pandemic, fears of COVID-19 were real. The majority of mothers who participated in this study decided to avoid visiting the hospital to seek a medical check-up or antenatal care. However, a pregnant woman with HIV has no choice to access Prevention of Mother to Child of HIV Transmission in a public hospital to minimise the risk of HIV transmission to her baby.

The below quote was taken from a letter from Yana, a 25-year-old mother living with HIV in Indonesia. The letter reflected her journey, her struggle, and life accessing antenatal care for her delivery during the pandemic:

I came to the hospital to give birth; I told them I have B20 (a medical term for HIV). But I was considered a badly behaved woman, who was going to infect health workers? Nevertheless, I was a good mother. And I was afraid of infecting my baby and the health workers with HIV. I was stigmatised. I did not get any respectful antenatal service. I was accused of being an irresponsible mother and having multiple [sexual] partners. I am the head of the family and the breadwinner. Alhamdulillah, I thank God. My three children are HIV-negative (Yana)

Yana is one of the three pregnant, mothers living with HIV who accessed FPAR, which facilitated an empowerment process for her to analyse and write about her situation and to share her story.

She recounted that in October 2020, she was rushed to hospital to deliver her fourth baby. Yana knew she needed to access Prevention of Mother-to-Child of HIV transmission (PMTCT) services and that these were only available at one particular public hospital. Her first three children did not have HIV, after she knew her HIV status in 2018, and decided to access PMTCT services and administer ARV therapy. Yana also knew she needed to disclose her HIV status to protect the doctors, midwives, and nurses from

HIV transmission and also so she could access prophylaxis therapy for her baby after her delivery.

Yana was treated in the Emergency Room and was asked screening questions related to COVID-19. Yana said that she was treated well by the health workers until she disclosed her HIV status. After she disclosed her HIV status, she said the nurse reacted with physical violence towards her, and demanded from her: ‘why didn’t you tell us at the first stage?’ A midwife also added, ‘for me, I prefer to treat Covid-19 patients than HIV-patients’<sup>11</sup>.

Yana complained to people at the hospital that it was demoralising to be treated in this manner. Finally, Yana received the proper antenatal care treatment but only after she insisted on seeing another doctor.

*Nika’s story: is it better to disclose your HIV status or not during the COVID-19 pandemic?*

In July 2020, 33-year-old HIV-positive Nika suffered from appendicitis and needed to undergo surgery. Nika shared her story after her hospitalisation. Nika is one out of 15 women living with HIV in this study who decided not to disclose her HIV status when she first accessed health services in the early part of the COVID-19 pandemic. Sadly, in July 2021, Nika passed away due to COVID-19.

She decided not to disclose her HIV status because she worried that she would not receive proper and respectful care. Nika believed that HIV-related stigma became worse during the pandemic. She revealed that every patient entering the hospital was suspected of having COVID-19 and if a patient then disclosed their HIV status they would face a difficult time getting treated. She recounts that

[In July 2020] Yes, I seek health services in a public hospital; I do not disclose my HIV status. There is a strong stigma of being an HIV-positive mother; I cannot imagine if I disclose my HIV status. I do not want to open my HIV status. You know why? I access third-class facilities (there are 5-8 patients in a room), stigma is strong during the Covid-19 pandemic (every patient was suspected of having Covid-19). I am alone during my hospitalisation; no

companion (from my family) was allowed. If I disclosed my HIV status, people would not treat me, they will run from me, and no one will take care of me, and no one will inject the medicine for me. In my observation, health workers are more afraid of HIV than Covid-19.<sup>11</sup>

In February 2021, Nika was sick again and was rushed to a hospital. She was coughing and had difficulty breathing. She was quickly diagnosed as having COVID-19 and was treated in an isolation room for 10 days. Nika expressed her experiences through her diary notes (see below). Sadly, Nika passed away in July 2021 from COVID.

Saturday, 6 February 2021.

In the morning, I was very weak and asked my parent to take me to the hospital. When I arrived at the hospital, I visited the emergency room straight away. I was checked and diagnosed with Covid-19, even though I had not been tested for Covid-19. My shortness of breath and severe coughing were similar to Covid-19 symptoms [so the doctors assumed I had it]. I was treated in an isolation room along with one other Covid-19 patient. No health workers treat me from the morning to the afternoon. I felt so weak and had difficulty breathing. At 2 pm, a nurse took my blood and did an infusion, and gave me oxygen. At 9 pm, I was moved to another isolation room where I was by myself . . . Then I was moved to another room after the Covid-19 result showed negative (Nika).

*Tiki and Nur: fighting COVID-19 stigma to ensure the health of themselves and their children*

During the pandemic, people who needed hospitalisation were often reluctant to seek treatment because of rumours that every person entering a hospital would be diagnosed with COVID-19. This section focuses on the experiences of two women living with HIV, who accessed health services during the first year of the COVID-19 pandemic, despite the rumours, to seek treatment for their children.

Tiki (33 years old) and Nur (38) disclosed their HIV status to gain proper treatment for their children, who also have HIV. As such, they were able to ensure that their children were provided with the proper HIV care. Nur was able to seek treatment to

prevent her second baby from contracting HIV during the pandemic, though her first child acquired HIV due to late notification of her HIV status.

Tiki decided to visit a public hospital in her village as her son lives with HIV; he is 5 years old. During the pandemic, he suffered from a tumour on his neck. Tiki wrote in her diary:

Dear my story. My days, my life is not easy. I open my eyes at midnight, my heart beating, and sometimes I want to give up. Many friends ask about my son's disease, [they have] many questions, they may show they care, [but] I only answered that my son suffers from a small tumour on his neck. I know it is an opportunistic infection from his low immunity due to HIV. However, I am sure God (Allah) knows I can pass this trial, and I know it is not easy to live with HIV at a young age with my youngest son. (Tiki, a wife of a husband without HIV)

Initially, she was afraid of visiting the hospital due to rumours of COVID-19 in hospitals and that everyone would be tested. After an online consultation with the doctor in the VCT centre, the doctor asked her to bring her son to the hospital on February 2021. It took 4 hours from her village to get there. Tiki noted that there was no need to feel afraid of visiting hospitals and she fought against the rumours surrounding COVID-19.

I feel the healthcare centre is more humane during the pandemic. The health workers treated my son very well, and they were full of smiles before and after his operation. The doctor did not discuss Covid-19 or [the] tests. The health workers focused on my child's health condition, and I feel relief.

In November 2020, Nur, was into her second pregnancy and needed to treat her malnourished daughter, Ana (18 months). She needed to stay for a week in a public hospital. She recalled that a doctor called on her in the emergency room, and as it was a crowded room, she disclosed Nur's first child's HIV status with a low tone of voice in the corner of the room.

It was like a 'thunderstorms' for Nur. Then, a week after her daughter's hospitalisation, Nur's husband was treated in the intensive care unit (ICU) room due to a complication of Tuberculosis and HIV, and Nur needed to prepare for her caesarean section to minimise HIV risk to her second baby. After

the recovery of her husband and her delivery, Nur needed to go to hospital every month. One driver asked her 'mom, what do you need to go to hospital during this pandemic, can you just immunize your child in the closer public health center?' Nur answered: 'in my body and my first child body, there is [a HIV] uncured disease, I do not be afraid of Covid-19'.

From Tiki and Nur's experience, caring for their HIV-positive children and being brave enough to access health services for their children suggests that they wanted to protect their children from any harm. In this way, Tiki, along with Nur and her husband, fight against HIV stigma by accessing healthcare for their child. By sharing their stories and using the FPAR process, they hope to reduce the stigma for mothers and children living with HIV.

### Discussion

Women living with HIV are aware that they will face stigma from family, health workers, friends, and neighbours. This article highlights how women living with HIV are negatively labelled by society and health services. The normalisation of institutional stigma and discrimination is rampant in Indonesia's health setting for women living with HIV, including disclosing HIV's patient status and the low priority of health services for these women.<sup>5,12</sup> Therefore, they need to consider to whom they disclose their HIV status. Consequently, HIV-related stigma is considered the main factor behind the low uptake of adherence to HIV prevention and treatment services.<sup>2,4-6</sup>

During the pandemic, women living with HIV needed to be brave enough to seek health services, while most people may avoid seeking them (Figure 6). The prospect of every patient being diagnosed with COVID-19 was rampant in the community in 2021.<sup>11</sup>

Not all people living with HIV in Indonesia dare to speak up and argue with health workers. Unfortunately, the lack of professionalism of health workers and the stigmatisation of HIV patients are still problems that cannot be overcome easily. As we can see from Yana's story, it is necessary to have a brave and confident voice like hers, and for Tiki's and Nur's story to help fight the stigma around COVID-19 and HIV, especially for the sake of their children's health. Sadly,

the number of those who are able to do this remains small, as most people choose to remain silent because they are rendered powerless.

As a result, understanding stigma requires consideration of the intersectional influences of the broader social, cultural, and economic factors that structure stigma beyond the level of the individual.<sup>13</sup> Women living with HIV need to be resilient, drawing on support from their families, supportive health workers to access health services. In addition, stigmatised groups, like women living with HIV, may avoid COVID-19 testing, disclose HIV status in health services and avoid accessing health services during their sickness. Health services need to work with peer support for women living with HIV (non-governmental organisation related to HIV) to provide a safe environment to get the right health services.<sup>18</sup>

At the policy level, the Indonesian government needs to create supportive health systems, including peer education for health workers who can provide safety and confidentiality for women living with HIV.<sup>5,11</sup> Therefore, the women feel safe, feel protected, and appreciated as good and religious mothers and wives to reduce the institutionalised stigma in society. In this context, we suggest that the Ministry of Health, in collaboration with the Ministry of Education, needs to include sexual and reproductive health rights and gender equality, particularly for women living with HIV, in the health curriculum.

## Conclusion

In this article, we have explored how women who are living with HIV access medical care during pandemic times. We revealed that women face difficult decisions, especially regarding whether to disclose their HIV status or not. Given the enduring stigma of living with HIV, many women are rightly fearful of revealing their status as they know the care they receive will be jeopardised. Medical professionals are still afraid of HIV in Indonesia because they lack proper education around transmission. COVID-19 has given personal medical excuses not to treat women with HIV because healthcare resources are so stretched. But many women are bravely disclosing their status and demanding they receive proper healthcare, especially when they are pregnant and have young children

We hope that this article shows that it is important to listen to women's stories, especially around HIV and COVID-19. While COVID-19 patients need to be prioritised, this should not be at the expense of women living with HIV. Governments need to ensure that women living with HIV, especially mothers, can access the healthcare they need for themselves and their children. Indeed, for two mothers we spoke to, they received good HIV healthcare for their children and as such, it is possible for some, yet not for all in Indonesia to access HIV care.

## Author contributions

**Najmah Najmah:** Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Visualization; Writing – original draft; Writing – review & editing.

**Sharyn Graham:** Conceptualization; Data curation; Formal analysis; Funding acquisition; Methodology; Project administration; Supervision; Writing – review & editing.

**Kusnan Kusnan:** Data curation; Formal analysis; Investigation; Writing – review & editing.

**Tom Graham Davies:** Software; Supervision; Validation; Writing – review & editing.

## Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Alumni Grant Scheme (AGS) Round 2, Australian Award for Indonesian. Available on <https://www.australiaawardsindonesia.org/project/detail/189/15/to-get-tested-or-not-a-project-to-reduce-stigma-around-Covid-19-and-hiv-testing-in-indonesia>

## Ethical approval

Ethical approval no: 002/UN9.FKM/TU.KKE/2021 by health research ethics committee of Faculty of Public Health Sriwijaya University.

## References

1. Closson K, Lee M, Gibbs A, *et al.* When home is not a safe place: impacts of social distancing



- directives on women living with HIV. *AIDS Behav* 2020; 24: 3017–3019.
2. Davies SG and Najmah. Im/moral healthcare: HIV and universal health coverage in Indonesia. *Sex Reprod Health Matters* 2020; 28: 1785377.
  3. Marzialli ME, Card KG, McLinden T, *et al.* Physical distancing in Covid-19 may exacerbate experiences of social isolation among people living with HIV. *AIDS Behav* 2020; 24: 2250–2252.
  4. Butt L. Sexual tensions HIV positive women in Papua. In: Davies SG (ed.) *Sex and sexualities in contemporary Indonesia: sexual politics, health, diversity and representations*. London: Routledge, 2015, pp. 109–128.
  5. Najmah AS and Davies SG. Perceptions of and barriers to HIV testing of women in Indonesia. *Sex Reprod Health Matters* 2020; 28: 1848003.
  6. Bennett LR and Davies SG. Sexual morality and the silencing of sexual health within Indonesian infertility care. In: Bennett LR and Davies SG (eds) *Sex and sexualities in contemporary Indonesia*. London: Routledge, 2016, pp. 148–166.
  7. Anindita M, Shaluhiah Z and Suryhoputro A. Non-Disclosure of HIV Positive Status of Women to their Partners: Implication for PMTCT in Central Java. *Jurnal Promosi Kesehatan Indonesia* 2013; 8(1). <https://core.ac.uk/reader/85036068>
  8. Rahmalia A, Wisaksana R, Meijerink H, *et al.* Women with HIV in Indonesia: Are they bridging a concentrated epidemic to the wider community? *BMC Research Notes* 2015; 8(1): 1.
  9. Hargreaves J, Davey C, Auerbach J, *et al.* Three lessons for the Covid-19 response from pandemic HIV. *Lancet* 2020; 7: e309–e311.
  10. Joska JA, Andersen L, Rabie S, *et al.* Covid-19: increased risk to the mental health and safety of women living with HIV in South Africa. *AIDS Behav* 2020; 24: 2751–2753.
  11. Najmah K and Davies SG. Endless stigma of HIV and covid-19. *Inside Indonesia*, 31 May 2021, <https://www.insideindonesia.org/endless-stigma-of-hiv-and-covid-19>
  12. Butt L. Can you keep a secret? Pretences of confidentiality in HIV/AIDS counseling and treatment in eastern Indonesia. *Med Anthropol* 2011; 30: 319–338.
  13. Parker R and Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med* 2003; 57: 13–24.
  14. Mitchell CM and Sommer M. Participatory visual methodologies. *Glob Public Health* 2016; 11: 521–527.
  15. Maguire P. Considering more feminist participatory research: what's congruency got to do with it? *Qual Inq* 1996; 2: 5–11.
  16. Maguire P. *Doing participatory research: a feminist approach*. Amherst, MA: The Centre for International Education, University of Massachusetts, 1987.
  17. Saldana J. *The coding manual for qualitative researchers*. London: SAGE, 2016.
  18. Nydegger LA and Hill MJ. Examining Covid-19 and HIV: the impact of intersectional stigma on short- and long-term health outcomes among African Americans. *Int Soc Work* 2020; 63: 655–659.