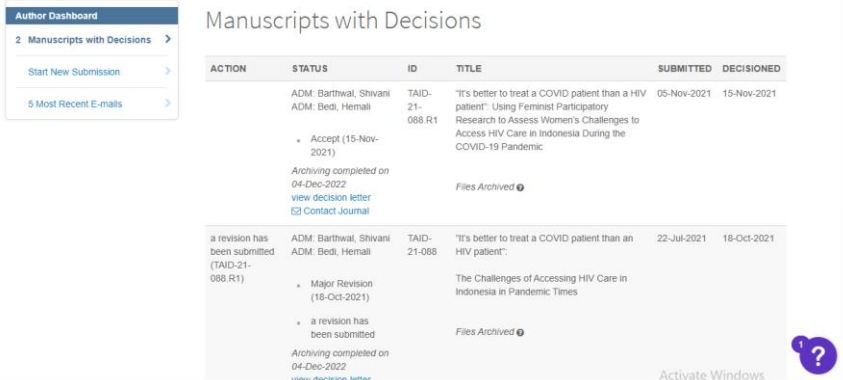


[KORESPONDENSI]

'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 (Penulis Pertama dan Korespondensi), Scopus Q4

<https://journals.sagepub.com/doi/full/10.1177/20499361211064191>

[Submission and revision in the system]



The screenshot displays an 'Author Dashboard' with a sidebar on the left containing '2 Manuscripts with Decisions', 'Start New Submission', and '5 Most Recent E-mails'. The main area is titled 'Manuscripts with Decisions' and features a table with columns for ACTION, STATUS, ID, TITLE, SUBMITTED, and DECISIONED.

ACTION	STATUS	ID	TITLE	SUBMITTED	DECISIONED
	ADM: Barthwal, Shivani ADM: Bedi, Hemali	TAID-21-088 R1	"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	05-Nov-2021	15-Nov-2021
	Accept (15-Nov-2021) Archiving completed on 04-Dec-2022 view decision letter Contact Journal		Files Archived		
a revision has been submitted (TAID-21-088 R1)	ADM: Barthwal, Shivani ADM: Bedi, Hemali	TAID-21-088	"It's better to treat a COVID patient than an HIV patient": The Challenges of Accessing HIV Care in Indonesia in Pandemic Times	22-Jul-2021	18-Oct-2021
	Major Revision (18-Oct-2021) a revision has been submitted Archiving completed on 04-Dec-2022 view decision letter		Files Archived		

[corresponding authors from editors]

Therapeutic Advances in Infectious Disease

Decision Letter (TAID-21-088)

From: TAInfectiousDisease@sagepub.co.uk
To: najem240783@gmail.com
CC:
Subject: Therapeutic Advances in Infectious Disease - Decision on Manuscript ID TAID-21-088
Body: 18-Oct-2021

Dear Hrs Sijmah,

Manuscript ID TAID-21-088 entitled "It's better to treat a COVID patient than an HIV patient": The Challenges of Accessing HIV Care in Indonesia in Pandemic Times" which you submitted to Therapeutic Advances in Infectious Disease, has been reviewed. The comments of the reviewer(s) are included at the bottom of this letter.

The reviewer(s) have recommended publication, but also suggest some revisions to your manuscript. Therefore, I invite you to respond to the reviewer(s) comments and revise your manuscript.

To revise your manuscript, log into <https://mc.manuscriptcentral.com/taid> and enter your Author Centre, where you will find your manuscript title listed under "Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

You will be unable to make your revisions on the originally submitted version of the manuscript. Instead, revise your manuscript using a word processing program and save it on your computer. Please also highlight the changes to your manuscript within the document by using the track changes mode in MS Word or by using bold or colored text.

Once the revised manuscript is prepared, you can upload it and submit it through your Author Centre.

When submitting your revised manuscript, you will be able to respond to the comments made by the reviewer(s) in the space provided. You can use this space to document any changes you make to the original manuscript. In order to expedite the processing of the revised manuscript, please be as specific as possible in your response to the reviewer(s).

IMPORTANT: Your original files are available to you when you upload your revised manuscript. Please delete any redundant files before completing the submission.

Because we are trying to facilitate timely publication of manuscripts submitted to Therapeutic Advances in Infectious Disease, your revised manuscript should be uploaded as soon as possible. If it is not possible for you to submit your revision in a reasonable amount of time, we may have to consider your paper as a new submission.

Once again, thank you for submitting your manuscript to the Therapeutic Advances in Infectious Disease and I look forward to receiving your revision.

Sincerely,
Andrés F. Henao-Martínez, MD
Editor-in-Chief
Therapeutic Advances in Infectious Disease
TAInfectiousDisease@sagepub.co.uk

Activate Windows
Go to Settings to activate Windows.

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

Comments

The authors present a study about discrimination and stigma against women during the COVID-19 pandemic in Sumatra.

This study is relevant for human rights advocacy and to highlight the lack of access to healthcare. For these reasons the authors should address some issues to support their data.

Major issues

Study groups and their results are not clear, first it is mentioned that two aspects were studied: exploring stigma of HIV in women and exploring the experiences of women with HIV when they try to access health services during COVID-19 pandemic. To achieve the goals, two study groups were established. The first group is clear: women with HIV, but the second group only indicates women who experienced stigma when they were tested for COVID-19, it does not indicate whether they were women with HIV or women without HIV, that is why the authors need to define the second group clearly. Also, it is not mentioned in the inclusion criteria.

By the way, figure 5 shows the perception of good mothers by a non-HIV woman, but it is not clear whether non-HIV women participated in this study.

In the manuscript it is mentioned that the study focused on the narratives of twenty women living with HIV, but only five narratives are shown (although on page 2, line 54 says three stories would be included) and the results of the rest of the participants are not discussed. Besides, the information in Table 1 is not clear, the differences between the X and V of the columns is confusing, you should discuss results shown in Table 1 to visualize the experience of the twenty participating women, their perception of HIV stigma and the difficulty accessing health services during the COVID-19 pandemic.

Authors need to be careful in their methods and include in the manuscript how they avoided biases in the women's perspective, as well as persuasion by researchers.

A more specific subtitle is suggested, such as: Women's Challenges of Accessing HIV Care in Indonesia in Pandemic Times.

Reviewer: 2

Comments to the Author

Reviewer comments:

1. Background:

Although there is no much data published on Stigma and Discrimination, it would be informative if the authors could give some background with evidence about the current stigma and discrimination situation. Proposed source: Stigma Index by Spiritia foundation.

2. The study does not show the timeline of when it was done, which year, for how long?

3. Sample size

a. How was the sample size was calculated?

4. How were the FDG participants allocated to groups? Was it based on age, HIV status or they share other characteristics (inclusion criteria)

5. Data collection tools: were these pre tested before the study?

6. Analysis:

a. Why the analyses only mention one person per analysis not group analysis/group's conclusion.

b. Was a software used or the data were analyzed manually?

c. Content analysis was used, was it a conceptual analysis or relational analysis

d. Was the translation and transcription done, who did these

Reviewer comments:

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

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Reviewer: 2

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- c. Content analysis was used, was it a conceptual analysis or relational analysis
- d. Was the translation and transcription done, who did these

8. A poem should not be put in the paper.

Editor(s)' Comments to Author:

Associate Editor

Comments to Author:

The Editors have reviewed your manuscript, and agree with the reviewers that the data presented is valuable. However, in addition to the reviewer's critique, we would like to suggest a number of changes to improve the suitability of the article for a scientific audience.

1. Title: Please revise your title to state the research question, study design, and location. This is the preferred format for the journal.

2. Abstract: We recommend a structured abstract that states the objective of the study, along with a summary of the key data or arguments and an overall conclusion. Please use the following headings to structure your abstract: Background; Objectives; Design; Methods; Results; Conclusion

3. Table 1: Please consider revising table 1 to present less information. We are concerned that including this amount of detail in the table risks identifying the study participants.

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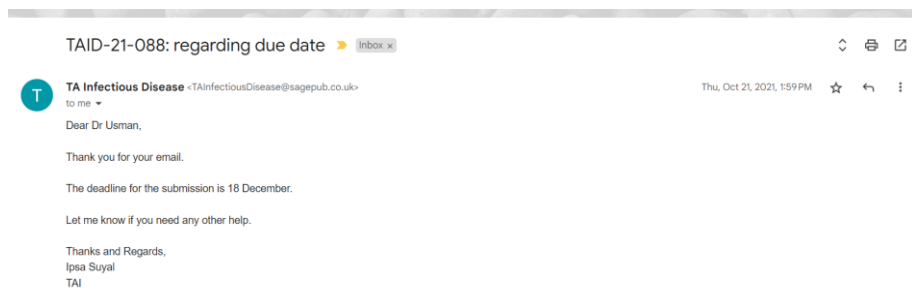
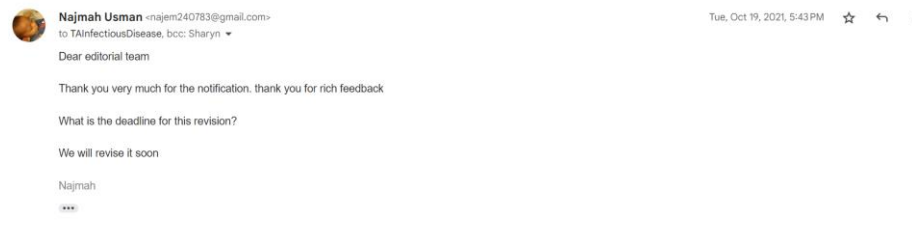
Comments

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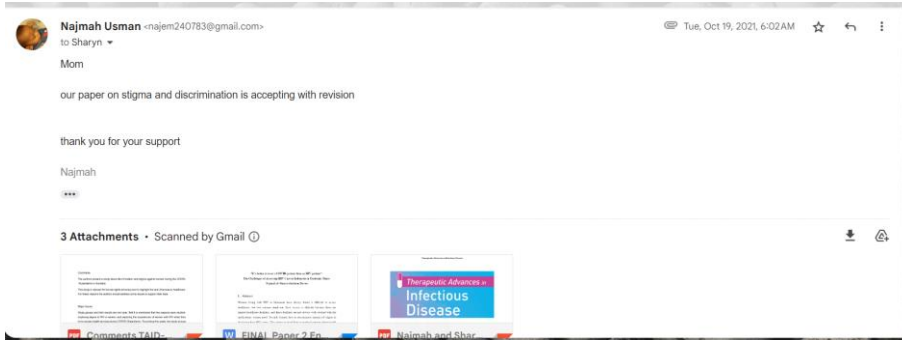
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[communication with another co-author, Prof Sharyn Graham Davies]



“It’s better to treat a COVID patient than an HIV patient”: Using Feminist Participatory Research to Assess Women’s Challenges to Access HIV Care in Indonesia During the Covid Pandemic Times

1. 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 HIV-positive women, by normalizing the discussion of HIV, and to empower health professionals to better understand the issues faced by HIV-positive women, and develop improved treatment practices.

Design

Our project was guided by a Feminist Participatory Action Research (FPAR) framework (1). FPAR refers to “a participatory and action-oriented approach to research that centres gender and women’s experiences both theoretically and practically.” (2) 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 (3).

Method

Purposive sampling and a thematic analysis was applied to focus group discussions with 20, HIV-positive and 20 non-HIV-positive women 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 paper 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.

Conclusions

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 program. This would normalize discussions of HIV-related topics, leading to improved health outcomes.

Keywords: HIV-positive women, mothers, health services, Covid-19 Pandemic, Indonesia.

Commented [A1]:

Reviewer 1:

A more specific subtitle is suggested, such as: Women’s Challenges of Accessing HIV Care in Indonesia in Pandemic Times

Editor

1. Title: Please revise your title to state the research question, study design, and location. This is the preferred format for the journal.

Najmah: has revised

Commented [A2]:

Editor:

2. Abstract: We recommend a structured abstract that states the objective of the study, along with a summary of the key data or arguments and an overall conclusion. Please use the following headings to structure your abstract: Background; Objectives; Design; Methods; Results; Conclusion

Najmah: has revised

2. 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 (4-6). This article will explore two main themes that came up from our research. The first theme relates to exploring the stigma of HIV for women from HIV-positive women's and non-HIV positive mothers' perception and experience. The second theme 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 disrespectfully. 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 HIV-positive mother fight against their self-stigma of HIV and against fears of contracting Covid-19 or fears of Covid-19 test to access the right health care right treatment for themselves and their HIV-positive children.

Indonesia has provided opportunities for women living with HIV to access health services under the National Health Insurance Program (5). 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 (2,3).

[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](#) (Anindita et al., 2013; Butt, 2015; Damar & du Plessis, 2010; Hidayana, 2012; Hidayana & Tenni, 2015; Ismail et al., 2018; Rahmalia et al., 2015). Despite this, women who disclose their HIV positive status, face discrimination in health services, including denial of confidentiality or privacy (5, 7, 8). This is compounded by a fear of HIV held by many healthcare workers who experience difficulty in discussing HIV in antenatal services, or treating HIV-positive women (9).

During the ongoing Covid-19 pandemic, women living with HIV face an incredibly difficult time due to health inequalities (10-12). 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](#),¹ [a mother of three children](#) lost her battle with HIV. While [Nika](#) had been successfully managing her HIV and her children's HIV, the Covid-19 pandemic changed this.

¹ For privacy reasons, all names are pseudonyms.

Commented [N3]: Reviewer 2

Background:

Although there is no much data published on Stigma and Discrimination, it would be informative if the authors could give some background with evidence about the current stigma and discrimination situation. Proposed source: Stigma Index by Spiritia foundation.

Answer

WE have revised this part and add other sources

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; [Oneng Nika](#) was thus too afraid to go to the hospital until [her](#) condition worsened. Sadly, by the time [Oneng she was](#) admitted, it was too late to save her life. [Oneng 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.

3. Research Method

The methods utilised in this project were a series of focus group discussions (FGDs), 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 record all data and field notes were also recorded. All participants gave verbal or written informed consent for inclusion into the study, including consent for 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, social media chats).

FGDs are particularly useful in gaining participant ideas and aspirations that might not have been accessible without group interaction (15). Interviews were undertaken in 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 (16). 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 (13). Alternatively, virtual FGD, interview, and participatory visual methods were chosen if there was Covid-19 restriction and the participants chose to do it.

[Insert Figure 1. Data Collection and Figure 2. Visual outcomes of participants]

FPAR 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 paper applies FPAR to explore women's diverse experiences of HIV-positive women 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 graduates with a Ph.D. 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.

Commented [A4]:

Review 2:

4. How were the FDG participants allocated to groups? Was it based on age, HIV status or they share other characteristics (inclusion criteria)

Answer:

We added the information

Najmah and third author worked together in data collection in the field and the third and fourth authors contributed to second opinion in data analysis and revision for draft for publication. 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 as Islamic studies enthusiast 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 HIV-positive mothers; and 2) 20 women ~~those who were pregnant or had been pregnant during~~ the Covid-19 ~~pandemic and~~ have experienced stigma while being tested for Covid-19 (Figure 1). **The recruitment was stopped till data saturation in the field.** 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 HIV-positive women during her Ph.D. research. In addition, two 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; 2) through the first author's peers in her workplace. Participants knew about the intention of the researchers to use this data for publication, and they consented to this as per the informed consent form. 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 a pregnant during the pandemic and (4) available to join a series of focus group discussions (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 HIV-positive mothers with HIV-positive children. The research were conducted between December 2020 to 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 were sent daily during fieldwork to the second author. The interpretations of the women's voices and presentations were coded in their original language (14). 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 manually set out by Saldana (14) 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

Commented [A5]:

Reviewer 1:

Study groups and their results are not clear, first it is mentioned that two aspects were studied: exploring stigma of HIV in women and exploring the experiences of women with HIV when they try to access health services during Covid-19 pandemic. To achieve the goals, two study groups were established. The first group is clear: women with HIV, but the second group only indicates women who experienced stigma when they were tested for Covid-19, it does not indicate whether they were women with HIV or women without HIV, that is why the authors need to define the second group clearly. Also, it is not mentioned in the inclusion criteria

Najmah: have revise it

Two groups: 1) HIV-positive women; 2) non HIV-positive women

Commented [A6]:

Reviewer 1:

In the manuscript it is mentioned that the study focused on the narratives of twenty women living with HIV, but only five narratives are shown (although on page 2, line 54 says three stories would be included) and the results of the rest of the participants are not discussed.

Answer:

We focus mainly on four stories of HIV-positive women to gain deep understanding on the themes

Commented [N7]: Reviewer 2

2. The study does not show the timeline of when it was done, which year, for how long.

Answer:

We have added the information

Commented [A8]:

Reviewer 1:

6. Analysis:

- a. Why the analyses only mention one person per analysis not group analysis/group's conclusion.
- b. Was a software used or the data were analyzed manually?
- c. Content analysis was used, was it a conceptual analysis or relational analysis
- d. Was the translation and transcription done, who did these

Answer:

a.??

b. manual coding

c. Thematic analysis

d. we only did translation for some quotations as both authors understand Indonesian language, therefore translation of all transcription is not undertaken. Coding and theme were developed in English

3. Fighting HIV stigma and discrimination: HIV-positive women's resilience in dealing HIV discrimination

4. Respondent's characteristics: HIV-positive women

In total, twenty women living with HIV and twenty non-HIV pregnant women during the pandemic contributed to this study. The HIV-positive women were aged between 21 and 49 years. Six were widowed and fourteen were married. Among non HIV-positive women, eleven identified themselves as a housewife or *ibu rumah tangga*, and nine of them were employed. Education levels ranged from between 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)).²

5. Disclosing HIV-Positive Status and Covid Testing

The majority of the twenty 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 twenty did not disclose their positive HIV status to their neighbors.

Only ten women accessed a Covid-19 test out of 18 pregnant women during pandemic as they delivered their babies or was hospitalised in a hospital. 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 five out of 20 women who were tested with HIV, nine were tested for Covid-19 when they accessed antenatal care in *puskesmas* or hospital.

6. 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 Indonesian context, stigma can be interpreted as shame or *malu*. HIV-positive mothers defined stigma as meaning bullying (*ngatoi*), insulting (*menghina*), isolating (*mengucilkan*), being fearful (*takut*).

When faced with the decision to disclose or not to disclose, we found that women are negatively impacted either way. If they decide 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 HIV-positive people but also members of high-risk groups such as sex workers, gay men, intravenous drug users, and also to those HIV-negative people who live with them.

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

² As at 4/11/2021.

Our research revealed many stigmatized perceptions about HIV-positive married women. All of which were pejorative. Stigmatized 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, 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*).

[Insert Figure 3. Label on HIV-positive women and Figure 4. HIV and COVID-19 intersecting]

Sadly these beliefs are so widespread in the community, it is not uncommon for them to be expressed in public health settings (6). 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 subjected to discrimination by others towards their own children.

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

One, non-HIV-positive, pregnant woman we spoke to, revealed when we asked what were her perceptions of HIV? She answered spontaneously "HIV is a dirty disease" (*penyakit kotor*). Another participant added 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).

[Insert Figure 5. Perception of a good mothers and wives]

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).

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

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. Though stigma relating to Covid-19 does not have the moral judgment attached to it, like HIV, 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 HIV-positive woman 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, HIV-positive mothers 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 were free of 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."

Yana complained to people at the hospital that it was demoralizing 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 HIV-positive women 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.

In February 2021, Nika was sick again and was rushed to hospital. She was coughing and had difficulty breathing. She was quickly diagnosed as having Covid-19 and was treated in an isolation room for ten 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 HIV-positive children

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

Tiki (33 years old) and Nur (38) disclosed their HIV status to gain proper treatment for their children and were able to ensure that their HIV-positive children were provided with the proper care. Nur was able to seek treatment to prevent her second baby from contracting HIV during the pandemic, though she needed to raise her first HIV-positive child 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 five years old. During the pandemic, he suffered from a tumor 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 with non HIV-positive husband).

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 four 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 her in the emergency room in a public hospital, 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, one week after her daughter's hospitalisation, Nur's husband was treated in the ICU room due to a complication of Tuberculosis and HIV, and Nur needed to prepare her caesarean section to minimize 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 story, and using the FPAR process, they hope to reduce the stigma for both HIV-positive mothers and children.

7. Discussion

HIV-positive women are aware that they will face stigma from family, health workers, friends, and neighbours. This article highlights how HIV-positive women are negatively labeled by society and health services. The normalization of institutional stigma and discrimination is rampant in Indonesia's health setting for women living with HIV, including disclosing HIV's patient status and low priority of health services for HIV-positive women (8, 15). 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 and poor adherence to HIV prevention and treatment services (20). During the pandemic, HIV-positive women needed to be brave enough to seek health services while most people may avoid seeking health services. The prospect of every patient being diagnosed with Covid-19 was rampant in the community into 2021 (12). We argue that the women may lose either way, through disclosing or not disclosing their HIV status in a health setting. 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 (16). HIV-positive women need to be resilient, drawing on support from their families, supportive health workers to access health services for the sake of their children and their health. 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 supports for HIV-positive women (Non-governmental organisation related to HIV) to provide a safe environment to get the right health services (17).

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 HIV-positive women (8, 12). Therefore, the women feel safe, feel protected, and appreciated as good and religious mothers and wives to reduce the institutionalized 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 HIV-positive women, in the health curriculum.

[Insert: **Figure 6: HIV-positive resilience in fighting HIV and COVID-19 stigma during Pandemic**
(Developed by Najmah)]

8. Conclusion

In this paper, we have explored how women 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 health care resources are so stretched. But many women are bravely disclosing their status and demanding they receive proper health care, 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.

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9. Ethical approval

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

10. An author contribution

The first and second authors designed the research protocol, data analysis and writing of the manuscript. The first author was responsible for transcribing the interviews, FGDs and visual outcomes and writing the first draft for publication. The second author assisted in translating quotations into English. The third author was responsible to do investigation with the first author. The second and fourth author was responsible to revising manuscript and supervision.

11. Conflict of Interest

None to declare

12. Funding statement

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>

“It’s better to treat a COVID patient than an HIV patient”: Using Feminist Participatory Research to Assess Women’s Challenges to Access HIV Care in Indonesia During the Covid Pandemic Times

13. 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 HIV-positive women, by normalizing the discussion of HIV, and to empower health professionals to better understand the issues faced by HIV-positive women, and develop improved treatment practices.

Design

Our project was guided by a Feminist Participatory Action Research (FPAR) framework (1). FPAR refers to “a participatory and action-oriented approach to research that centres gender and women’s experiences both theoretically and practically.” (2) 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 (3).

Method

Purposive sampling and a thematic analysis was applied to focus group discussions with 20, HIV-positive and 20 non-HIV-positive women 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 paper 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.

Conclusions

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 program. This would normalize discussions of HIV-related topics, leading to improved health outcomes.

Keywords: HIV-positive women, mothers, health services, Covid-19 Pandemic, Indonesia.

Commented [A9]:

Reviewer 1:

A more specific subtitle is suggested, such as: Women’s Challenges of Accessing HIV Care in Indonesia in Pandemic Times

Editor

1. Title: Please revise your title to state the research question, study design, and location. This is the preferred format for the journal.

Najmah: has revised

Commented [A10]:

Editor:

2. Abstract: We recommend a structured abstract that states the objective of the study, along with a summary of the key data or arguments and an overall conclusion. Please use the following headings to structure your abstract: Background; Objectives; Design; Methods; Results; Conclusion

Najmah: has revised

14. 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 (4-6). This article will explore two main themes that came up from our research. The first theme relates to exploring the stigma of HIV for women from HIV-positive women's and non-HIV positive mothers' perception and experience. The second theme 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 disrespectfully. 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 HIV-positive mother fight against their self-stigma of HIV and against fears of contracting Covid-19 or fears of Covid-19 test to access the right health care right treatment for themselves and their HIV-positive children.

Indonesia has provided opportunities for women living with HIV to access health services under the National Health Insurance Program (5). 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 (2,3).

[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](#) (Anindita et al., 2013; Butt, 2015; Damar & du Plessis, 2010; Hidayana, 2012; Hidayana & Tenni, 2015; Ismail et al., 2018; Rahmalia et al., 2015). Despite this, women who disclose their HIV positive status, face discrimination in health services, including denial of confidentiality or privacy (5, 7, 8). This is compounded by a fear of HIV held by many healthcare workers who experience difficulty in discussing HIV in antenatal services, or treating HIV-positive women (9).

During the ongoing Covid-19 pandemic, women living with HIV face an incredibly difficult time due to health inequalities (10-12). 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,³ [a mother of three children](#) lost her battle with HIV. While Nika had been successfully managing her HIV and her children's HIV, the Covid-19 pandemic changed this.

³ For privacy reasons, all names are pseudonyms.

Commented [N11]: Reviewer 2

Background:

Although there is no much data published on Stigma and Discrimination, it would be informative if the authors could give some background with evidence about the current stigma and discrimination situation. Proposed source: Stigma Index by Spiritia foundation.

Answer

WE have revised this part and add other sources

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; [Oneng Nika](#) was thus too afraid to go to the hospital until [her](#) condition worsened. Sadly, by the time [Oneng she was](#) admitted, it was too late to save her life. [Oneng 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.

15. Research Method

The methods utilised in this project were a series of focus group discussions (FGDs), 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 record all data and field notes were also recorded. All participants gave verbal or written informed consent for inclusion into the study, including consent for 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, social media chats).

FGDs are particularly useful in gaining participant ideas and aspirations that might not have been accessible without group interaction (15). Interviews were undertaken in 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 (16). 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 (13). Alternatively, virtual FGD, interview, and participatory visual methods were chosen if there was Covid-19 restriction and the participants chose to do it.

[Insert Figure 1. Data Collection and Figure 2. Visual outcomes of participants]

FPAR 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 paper applies FPAR to explore women's diverse experiences of HIV-positive women 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 graduates with a Ph.D. 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.

Commented [A12]:

Review 2:

4. How were the FDG participants allocated to groups? Was it based on age, HIV status or they share other characteristics (inclusion criteria

Answer:

We added the information

Najmah and third author worked together in data collection in the field and the third and fourth authors contributed to second opinion in data analysis and revision for draft for publication. 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 as Islamic studies enthusiasm and the fourth author as an 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 HIV-positive mothers; and 2) 20 women ~~those who were pregnant or had been pregnant during~~ the Covid-19 ~~bandemid and~~ have experienced stigma while being tested for Covid-19 (Figure 1). **The recruitment was stopped till data saturation in the field.** 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 HIV-positive women during her Ph.D. research. In addition, two 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; 2) through the first author's peers in her workplace. Participants knew about the intention of the researchers to use this data for publication, and they consented to this as per the informed consent form. 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 a pregnant during the pandemic and (4) available to join a series of focus group discussions (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 HIV-positive mothers with HIV-positive children. The research were conducted between December 2020 to 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 were sent daily during fieldwork to the second author. The interpretations of the women's voices and presentations were coded in their original language (14). 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 manually set out by Saldana (14) 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:

4. HIV-related-stigma and discrimination
5. Disclosure or non-disclosure of HIV status in health settings

Commented [A13]:

Reviewer 1:

Study groups and their results are not clear, first it is mentioned that two aspects were studied: exploring stigma of HIV in women and exploring the experiences of women with HIV when they try to access health services during Covid-19 pandemic. To achieve the goals, two study groups were established. The first group is clear: women with HIV, but the second group only indicates women who experienced stigma when they were tested for Covid-19, it does not indicate whether they were women with HIV or women without HIV, that is why the authors need to define the second group clearly. Also, it is not mentioned in the inclusion criteria

Najmah: have revise it

Two groups: 1) HIV-positive women; 2) non HIV-positive women

Commented [A14]:

Reviewer 1:

In the manuscript it is mentioned that the study focused on the narratives of twenty women living with HIV, but only five narratives are shown (although on page 2, line 54 says three stories would be included) and the results of the rest of the participants are not discussed.

Answer:

We focus mainly on four stories of HIV-positive women to gain deep understanding on the themes

Commented [N15]: Reviewer 2

2. The study does not show the timeline of when it was done, which year, for how long.2

Answer:

We have added the information

Commented [A16]:

Reviewer 1:

6. Analysis:

- a. Why the analyses only mention one person per analysis not group analysis/group's conclusion.
- b. Was a software used or the data were analyzed manually?
- c. Content analysis was used, was it a conceptual analysis or relational analysis
- d. Was the translation and transcription done, who did these

Answer:

b.??

b. manual coding

c. Thematic analysis

d. we only did translation for some quotations as both authors understand Indonesian language, therefore translation of all transcription is not undertaken. Kodng and theme were developed in English

6. Fighting HIV stigma and discrimination: HIV-positive women's resilience in dealing HIV discrimination

16. Respondent's characteristics: HIV-positive women

In total, twenty women living with HIV and twenty non-HIV pregnant women during the pandemic contributed to this study. The HIV-positive women were aged between 21 and 49 years. Six were widowed and fourteen were married. Among non HIV-positive women, eleven identified themselves as a housewife or *ibu rumah tangga*, and nine of them were employed. Education levels ranged from between 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)).⁴

17. Disclosing HIV-Positive Status and Covid Testing

The majority of the twenty 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 twenty did not disclose their positive HIV status to their neighbors.

Only ten women accessed a Covid-19 test out of 18 pregnant women during pandemic as they delivered their babies or was hospitalised in a hospital. 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 five out of 20 women who were tested with HIV, nine were tested for Covid-19 when they accessed antenatal care in *puskesmas* or hospital.

18. 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 Indonesian context, stigma can be interpreted as shame or *malu*. HIV-positive mothers defined stigma as meaning bullying (*ngatoi*), insulting (*menghina*), isolating (*mengucilkan*), being fearful (*takut*).

When faced with the decision to disclose or not to disclose, we found that women are negatively impacted either way. If they decide 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 HIV-positive people but also members of high-risk groups such as sex workers, gay men, intravenous drug users, and also to those HIV-negative people who live with them.

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

⁴ As at 4/11/2021.

Our research revealed many stigmatized perceptions about HIV-positive married women. All of which were pejorative. Stigmatized 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, 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*).

[Insert Figure 3. Label on HIV-positive women and Figure 4. HIV and COVID-19 intersecting]

Sadly these beliefs are so widespread in the community, it is not uncommon for them to be expressed in public health settings (6). 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 subjected to discrimination by others towards their own children.

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

One, non-HIV-positive, pregnant woman we spoke to, revealed when we asked what were her perceptions of HIV? She answered spontaneously "HIV is a dirty disease" (*penyakit kotor*). Another participant added 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).

[Insert Figure 5. Perception of a good mothers and wives]

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).

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

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. Though stigma relating to Covid-19 does not have the moral judgment attached to it, like HIV, 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 HIV-positive woman 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, HIV-positive mothers 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 were free of 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."

Yana complained to people at the hospital that it was demoralizing 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 HIV-positive women 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.

In February 2021, Nika was sick again and was rushed to hospital. She was coughing and had difficulty breathing. She was quickly diagnosed as having Covid-19 and was treated in an isolation room for ten 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 HIV-positive children

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

Tiki (33 years old) and Nur (38) disclosed their HIV status to gain proper treatment for their children and were able to ensure that their HIV-positive children were provided with the proper care. Nur was able to seek treatment to prevent her second baby from contracting HIV during the pandemic, though she needed to raise her first HIV-positive child 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 five years old. During the pandemic, he suffered from a tumor 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 with non HIV-positive husband).

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 four 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 her in the emergency room in a public hospital, 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, one week after her daughter's hospitalisation, Nur's husband was treated in the ICU room due to a complication of Tuberculosis and HIV, and Nur needed to prepare her caesarean section to minimize 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 story, and using the FPAR process, they hope to reduce the stigma for both HIV-positive mothers and children.

19. Discussion

HIV-positive women are aware that they will face stigma from family, health workers, friends, and neighbours. This article highlights how HIV-positive women are negatively labeled by society and health services. The normalization of institutional stigma and discrimination is rampant in Indonesia's health setting for women living with HIV, including disclosing HIV's patient status and low priority of health services for HIV-positive women (8, 15). 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 and poor adherence to HIV prevention and treatment services (20). During the pandemic, HIV-positive women needed to be brave enough to seek health services while most people may avoid seeking health services. The prospect of every patient being diagnosed with Covid-19 was rampant in the community into 2021 (12). We argue that the women may lose either way, through disclosing or not disclosing their HIV status in a health setting.

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 (16). HIV-positive women need to be resilient, drawing on support from their families, supportive health workers to access health services for the sake of their children and their health. 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 supports for HIV-positive women (Non-governmental organisation related to HIV) to provide a safe environment to get the right health services (17).

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 HIV-positive women (8, 12). Therefore, the women feel safe, feel protected, and appreciated as good and religious mothers and wives to reduce the institutionalized 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 HIV-positive women, in the health curriculum.

[Insert: **Figure 6: HIV-positive resilience in fighting HIV and COVID-19 stigma during Pandemic**
(Developed by Najmah)]

20. Conclusion

In this paper, we have explored how women 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 health care resources are so stretched. But many women are bravely disclosing their status and demanding they receive proper health care, 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.

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21. Ethical approval

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

22. An author contribution

The first and second authors designed the research protocol, data analysis and writing of the manuscript. The first author was responsible for transcribing the interviews, FGDs and visual outcomes and writing the first draft for publication. The second author assisted in translating quotations into English. The third author was responsible to do investigation with the first author. The second and fourth author was responsible to revising manuscript and supervision.

23. Conflict of Interest

None to declare

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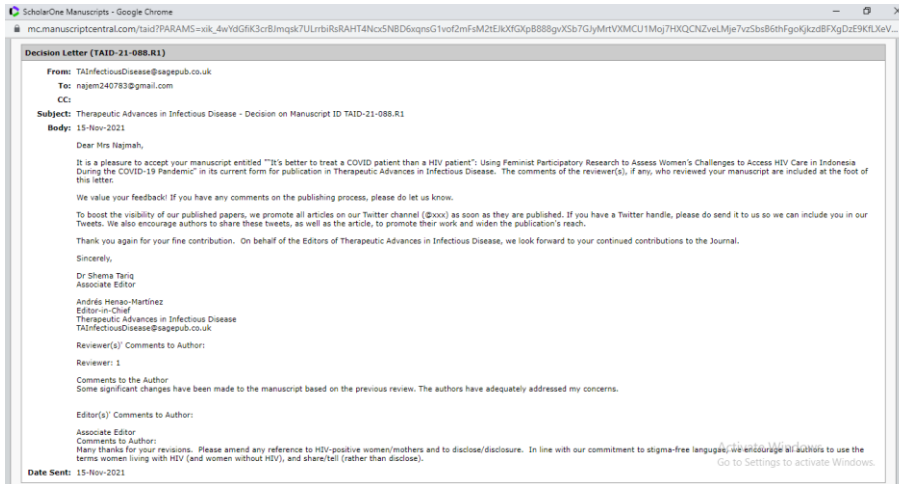
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Dear Mrs Najmah,

It is a pleasure to accept your manuscript entitled "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" in its current form for publication in Therapeutic Advances in Infectious Disease. The comments of the reviewer(s), if any, who reviewed your manuscript are included at the foot of this letter.

We value your feedback! If you have any comments on the publishing process, please do let us know.

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Thank you again for your fine contribution. On behalf of the Editors of Therapeutic Advances in Infectious Disease, we look forward to your continued contributions to the Journal.

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Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

Some significant changes have been made to the manuscript based on the previous review. The authors have adequately addressed my concerns.

Editor(s)' Comments to Author:

Associate Editor

Comments to Author:

Many thanks for your revisions. Please amend any reference to HIV-positive women/mothers and to disclose/disclosure. In line with our commitment to stigma-free language, we encourage all authors to use the terms women living with HIV (and women without HIV), and share/tell (rather than disclose).

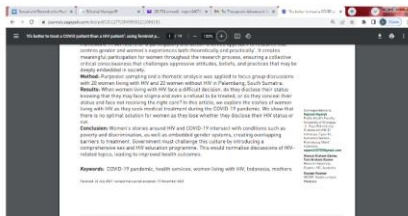


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Dear Bharti and Shivani

thank you for your quick response. It would be really appreciated if you could change this corresponding author najmah240783@gmail.com to najmah@fkm.unsri.com



[FINAL SUBMISSION]



**“It’s better to treat a COVID patient than an HIV patient”:
The Challenges of Accessing HIV Care in Indonesia in
Pandemic Times**

Journal:	<i>Therapeutic Advances in Infectious Disease</i>
Manuscript ID	Draft
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Complete List of Authors:	Najmah, Najmah; Public Health Faculty, University of Sriwijaya, Public Health; Kampung Pandai 13 Ulu, Davies, Sharyn ; Monash University, Director Herb Feith Indonesia Engagement Centre
Keywords:	
Abstract:	<p>Women living with HIV in Indonesia have always found it difficult to access healthcare; but two reasons stand out. First, access is difficult because there are limited healthcare facilities, and these facilities are not always well-stocked with the medications women need. Second, women face an enormous amount of stigma in disclosing their HIV-status. This stigma is faced both in medical settings where health care personnel suggest that ‘good’ women do not contract HIV, and at home where families blame women for contracting HIV. COVID-19 has exacerbated the difficulties women living with HIV face.</p> <p>Indonesia has struggled to contain COVID-19 and its healthcare services are stretched to breaking point. When women living with HIV thus try to access medical treatment, whether it is specifically for HIV or for other issues, they 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 paper we explore the stories of women living with HIV as they seek medical treatment during the COVID-19 pandemic. We show that there</p>

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	is no optimal solution for women as they lose whether they disclose their HIV status or not.

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The research protocol proposed by

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Principal in Investigator

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**"DI TES ATAU TIDAK: SEBUAH UPAYA UNTUK MENGURANGI STIGMA DALAM KONTEKS AKSES TES
COVID-19 DAN HIV DI INDONESIA"**

***"TO GET TESTED OR NOT: A PROJECT TO REDUCE STIGMA AROUND COVID-19 AND HIV TESTING
IN INDONESIA"***

Dinyatakan laik etik sesuai 7 (tujuh) Standar WHO 2011, yaitu 1) Nilai Sosial, 2) Nilai Ilmiah, 3) Pemerataan Beban dan Manfaat, 4) Risiko, 5) Bujukan/Eksploitasi, 6) Kerahasiaan dan Privacy, dan 7) Persetujuan Setelah Penjelasan, yang merujuk pada Pedoman CIOMS 2016. Hal ini seperti yang ditunjukkan oleh terpenuhinya indikator setiap standar.

Declared to be ethically appropriate in accordance to 7 (seven) WHO 2011 Standards, 1) Social Values, 2) Scientific Values, 3) Equitable Assessment and Benefits, 4) Risks, 5) Persuasion/Exploitation, 6) Confidentiality and Privacy, and 7) Informed Consent, referring to the 2016 CIOMS Guidelines. This is as indicated by the fulfillment of the indicators of each standard.

Pernyataan Laik Etik ini berlaku selama kurun waktu tanggal 4 Januari 2021 sampai dengan tanggal 4 Januari 2022

This declaration of ethics applies during the period January 4, 2021 until January 4, 2022

Indralaya, January 4, 2021
Head of the Committee,



Dr. Rosika Flora, S.Kep., M.Kes
NIP. 197109271994032004

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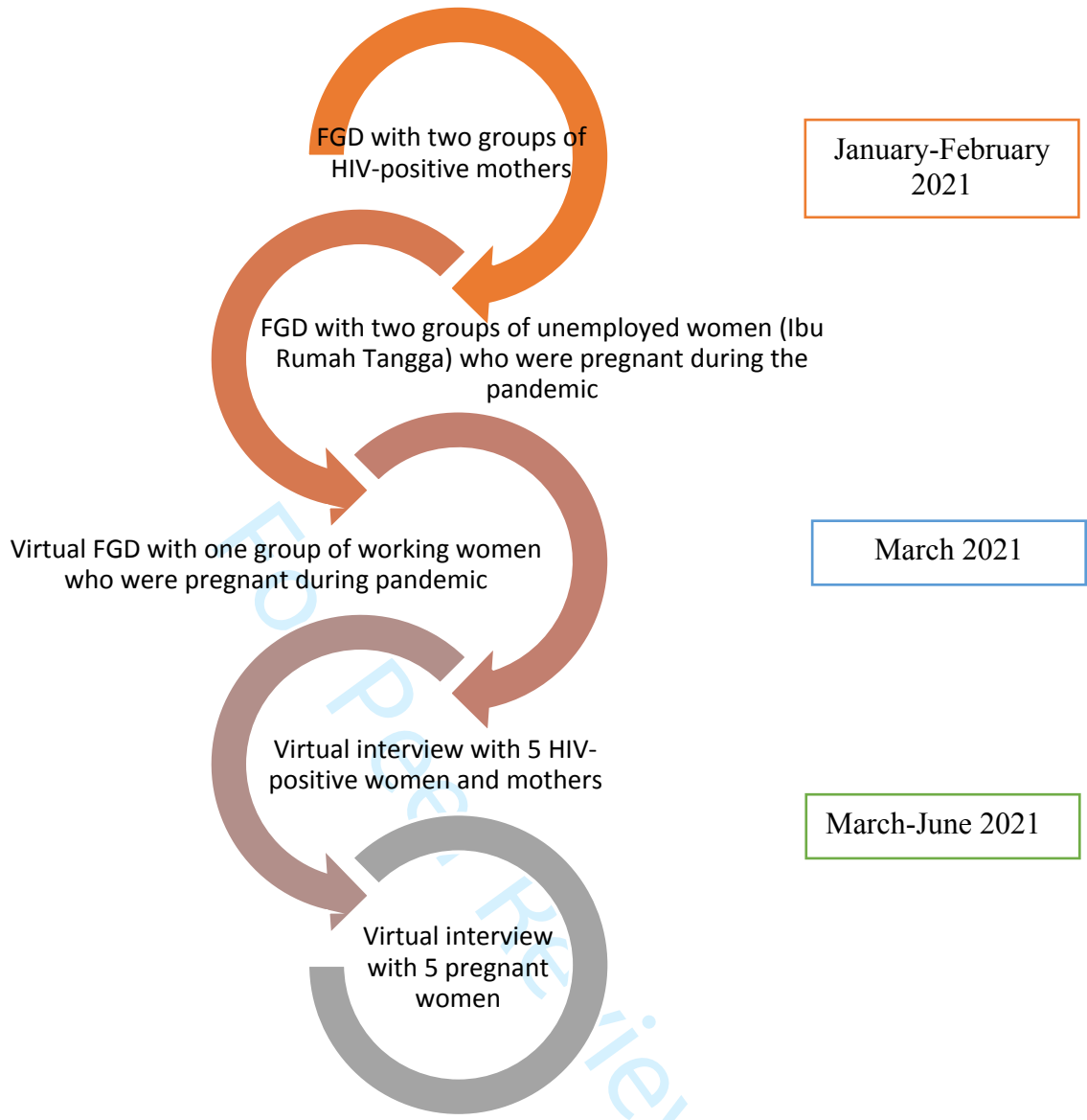


Figure 1. Data Collection Cycle

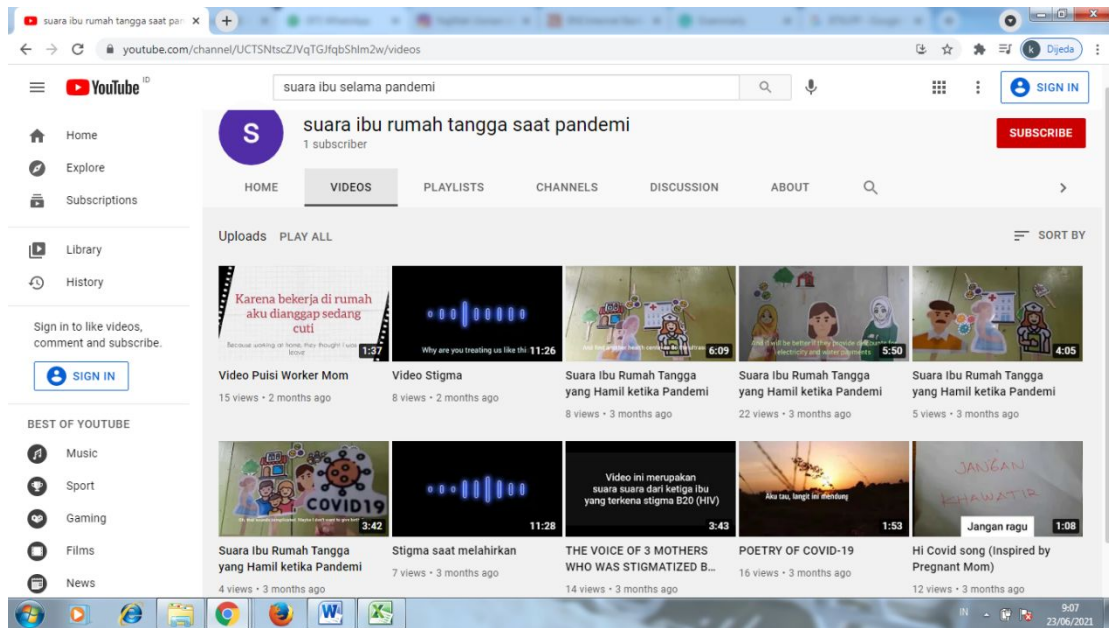


Figure 2. Visual outcomes of participants' action during research process

Link: <https://www.youtube.com/channel/UCTSNtscZJVqTGJfqbShlm2w/videos>

Note: 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 HIV-positive mothers together.

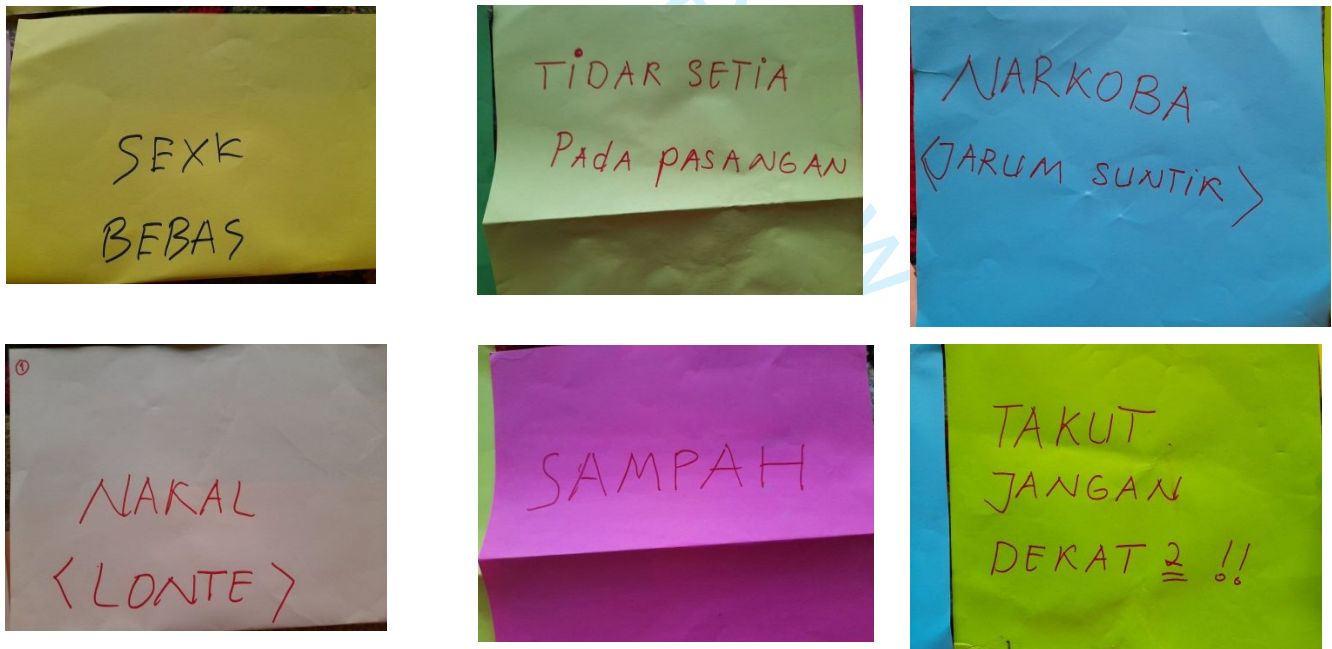


Figure 3: Label on HIV-positive women (wrote by a group of HIV-positive women in this study, Najmah's copyrights)

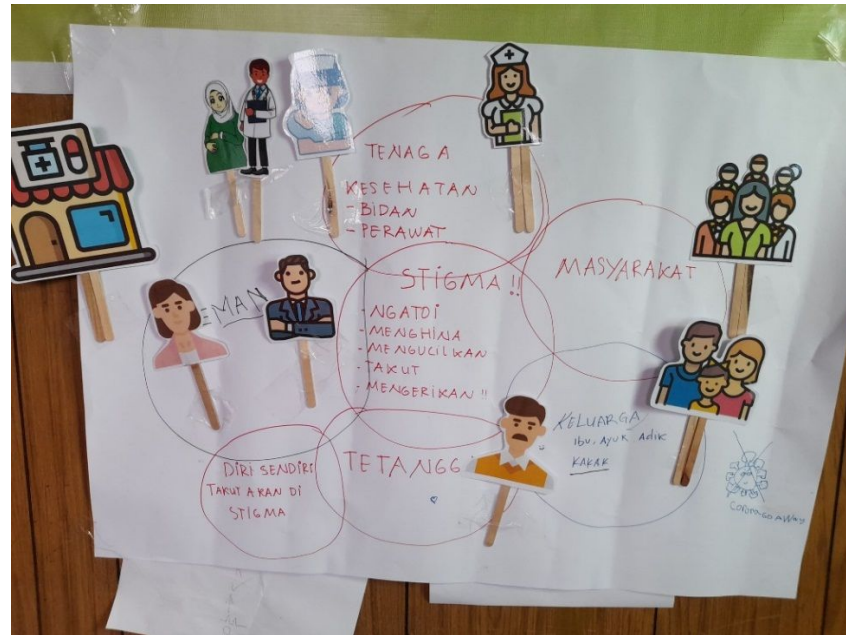


Figure 4: HIV and COVID-19 related stigma intersecting for mothers living with HIV from themselves (*diri sendiri*), family (*keluarga*), neighbour (*tetangga*), society (*masyarakat*), health (*tenaga kesehatan*) and friends (*teman*).

Note: Link video: <https://www.youtube.com/watch?v=MvuVKfgRvhw>

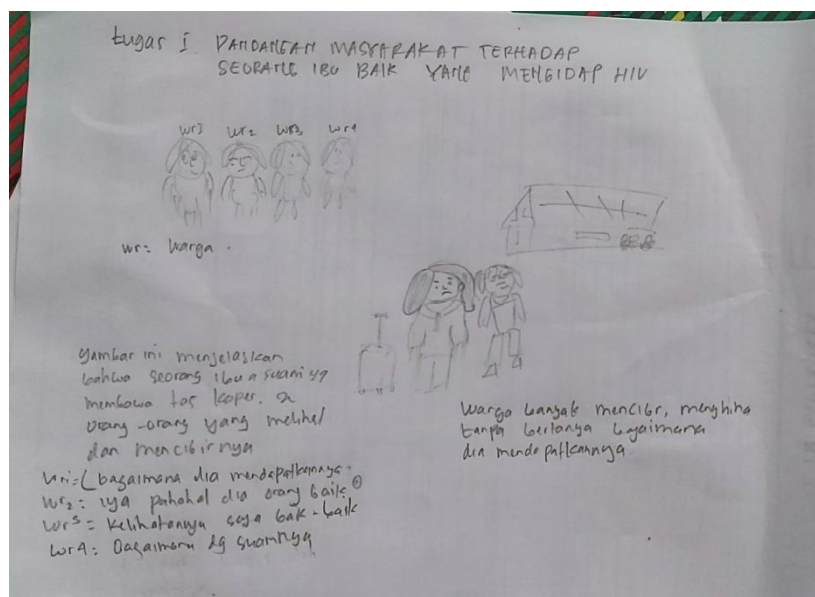


Figure 5: Perception of a good mothers and wives living with HIV (Najmah documentation, drawing by Rima, mother with three kids, non HIV)

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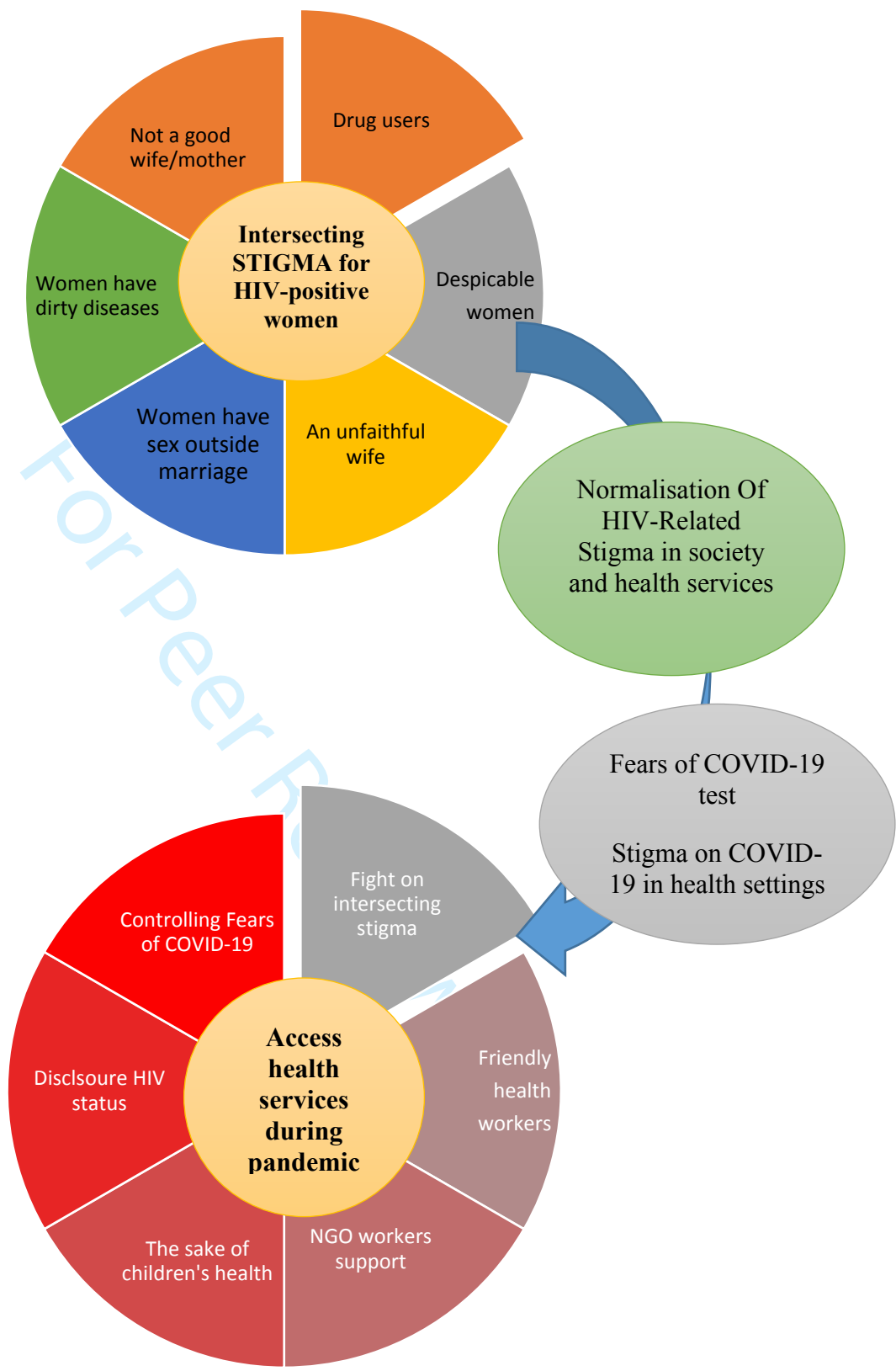


Figure 6: HIV-positive resilience in fighting HIV and COVID-19 stigma during Pandemic (Developed by Author A)

Table 1. Respondent's characteristics: HIV-positive women

Name	Age	Marital status & Owing house	Origins	Disclosure of HIV status			Experience of stigma and Discrimination		
				Family	Neighbours	Health Workers (not in HIV services)	Family	Neighbours	Health workers (not in HIV services)
1. Vela	25	Married Contracted house	Palembang	Sister and husband	X	X	X	-	V
2. Widi	34	Second married	Lahat	Second husband	X	X	X	-	V
3. Yana	25	Married Contracted house	Palembang	Husband and sister	X	V	X	-	V
4. Nur	36	Married Parent's house	Palembang	Husband and husband's family	V	X	X	-	X
5. Ika	36	Widow Owing house	Palembang	Mother, sister and brothers	X	X	X	-	V
6. Endah	49	Widow Parent's house	Palembang	Family	X	V	X	-	X
7. Mila	41	Widow Parent's house	Palembang	Parents and siblings	X	X	V	-	V
8. Viyah	40	Second married Owing house	Palembang	Husband's family	X	X	X	-	X
9. Oneng	44	Widow Parent's house	Palembang	Family	X	V	X	-	V
10. Nika	33	Divorce Parent's house	Palembang	Family	V	V	X	V	V
11. Tiki	33	Married Owing house	Lahat	Family	X	X	X	-	V
12. Rini	40	Widow Owing house	Palembang	Nuclear family	X	X	X	-	-
13. Mawar	44	Widow Owing house	Medan	Nuclear family	X	X	X	-	V
14. Xani	35	Married Owing house	Palembang	Family	X	X	X	-	V
15. Mona	33	Second married Contracted house	Palembang	Nuclear family	X	X	V	-	X
16. Putri	38	Married Owing house	Palembang	Husband	X	X	X	-	V
17. Maya	36	Second married Contracted house	Palembang	Parent and husband	X	X	X	-	X

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18. Mano	38	Married Parent's house	Palembang	husband	X	X	X	-	V
19. Bunga	33	Second married Owning house	Palembang	Sister and husband	X	X	X	-	V
20. Mulan	31	Second married Contracted house	Palembang	Second husband	X	X	X	-	X

Note:

V: yes, HIV-positive mothers disclose HIV status or did not experience stigma related to HIV in health settings

X: Not disclosed HIV status or did not experience stigma related HIV in health settings

For Peer Review

COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description Reported on Page No.	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	3
Occupation	3	What was their occupation at the time of the study?	3
Gender	4	Was the researcher male or female?	4
Experience and training	5	What experience or training did the researcher have?	4
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	1-2 in table documen
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4-5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	4-5
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	4
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	5-

Topic	Item No.	Guide Questions/Description	Reported on Page No.
correction?			
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	No
Derivation of themes	26	Were themes identified in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	Manual coding
Participant checking	28	Did participants provide feedback on the findings?	This is an ongoing process
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	6-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	6-13
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	This will be taken up in future publications

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**”It’s better to treat a COVID patient than an HIV patient”:
The Challenges of Accessing HIV Care in Indonesia in Pandemic Times**

1. Abstract

Women living with HIV in Indonesia have always found it difficult to access healthcare; but two reasons stand out. First, access is difficult because there are limited healthcare facilities, and these facilities are not always well-stocked with the medications women need. Second, women face an enormous amount of stigma in disclosing their HIV-status. This stigma is faced both in medical settings where health care personnel suggest that ‘good’ women do not contract HIV, and at home where families blame women for contracting HIV. COVID-19 has exacerbated the difficulties women living with HIV face.

Indonesia has struggled to contain COVID-19 and its healthcare services are stretched to breaking point. When women living with HIV thus try to access medical treatment, whether it is specifically for HIV or for other issues, they 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 paper 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.

Keywords: HIV-positive women, mothers, health services, COVID-19 Pandemic, Indonesia.

2. Introduction

In July 2021, Oneng, a mother of six children, lost her battle with HIV. While Oneng had been successfully managing her HIV and her children’s HIV, the COVID-19 pandemic changed this. Previously, Oneng had been able to access the medications she and her children needed. However, the pandemic diverted health resources away from HIV to COVID-19. Further, rumors were rife that if you went to the hospital, you would contract COVID-19; Oneng was thus too afraid to go to the hospital until her condition worsened. Sadly, by the time Oneng was omitted, it was too late to save her life.

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3 Oneng's story is just one of the stories we share below in this article about the impact
4 of the COVID-19 pandemic on HIV healthcare in Indonesia.
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Indonesia has provided opportunities for women living with HIV to access health services under the National Health Insurance Program (1) . 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 (2,3). Women who disclose face violations in health services, including not having a right to confidentiality or privacy, are blamed for contracting HIV (1,4–6). Further, the stigma surrounding HIV, and the silence surrounding HIV health care, means many health workers are afraid of discussing about HIV in antenatal services or treating HIV-positive women (1,7).

During the ongoing COVID-19 pandemic, women living with HIV face an incredibly difficult time due to health inequalities(8–10). 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 not to disclose their HIV status.

Indonesia's COVID-19 pandemic has thus created additional 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 (1,11,12). This article will explore two main themes that came up from our research. The first theme relates to exploring the stigma of HIV for women. The second theme 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 disrespectfully. In our second story, we tell of how Nika decided not to disclose her

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3 HIV status when she was diagnosed with COVID-19 in the hopes that she would
4 receive efficient and respectful healthcare. The third story tells of how HIV-positive
5 mothers fight against their self-stigma of HIV and against fears of contracting COVID-
6 19 or fears of COVID-19 test to access the right health care right treatment for
7 themselves and their HIV-positive children.
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10 11 12 13 **3. Methodology**

14 15 Research methodology: Feminist Participatory Action Research

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17 Our project was guided by a Feminist Participatory Action Research (FPAR)
18 framework. Patricia Maguire implicitly introduced the principles of FPAR in several
19 works (13,14). Maguire described her first experience with FPAR in a project with
20 Native American women survivors of sexual abuse, highlighting how building trust was
21 important in the research. Maguire (1996) introduced further considerations for FPAR,
22 such as creating meaningful participation for women throughout the research process
23 and ensuring outcomes that included a collective critical consciousness that challenged
24 oppressive attitudes, beliefs, and practices that may be deeply embedded in society (14).
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33 FPAR enabled the first and second author to work closely together with women. In
34 particular, we worked with women of reproductive age because this is a demographic
35 where we have particular expertise. Moreover, we focused on women from
36 marginalised groups, such as women living with HIV and women from low to middle-
37 income families. This paper applies FPAR to explore women's diverse experiences of
38 HIV-positive women accessing healthcare services, including antenatal care, PMTCT
39 services, and other health services.
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46 The first author is an epidemiologist and a public health lecturer at a public university
47 in Indonesia and graduates with a Ph.D. from Auckland University of Technology in
48 New Zealand. The second author is an anthropologist and has worked on research
49 projects in Indonesia for over 15 years. All authors communicate fluently in Bahasa
50 Indonesia and have a good grasp of Indonesian culture, political and social contexts.
51 Both authors identify as cis-gender women.
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Participant selection

The participants were recruited purposively from around Palembang, South Sumatra, Indonesia. There are two groups of women in this study: (1) HIV-positive mothers; and (2) those who 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 knows about living with HIV. The first author developed a close relationship with 15 HIV-positive women groups during her Ph.D. research. In addition, two NGO workers in the HIV field helped to spread the advertisement to their networks. For the second group, two COVID-safe methods of recruitment were used that promotions were applied: (1) by word of mouth to women; (2) through the first author's peers in her workplace. Participants knew about the intention of the researchers to use this data for publication, and they consented to this as per the informed consent form. During the process of rapport building, the researchers identified their reasons for interest in this topic and laid bare assumptions they had that were relevant.

The inclusion criteria of both groups were: (1) of reproductive age; (2) living in Palembang, South Sumatra; (3) having children or a pregnant women during pandemic and (4) available to join a series of focus group discussions (FGDs) or interviews, face-to-face or virtual meeting through WhatsApp. This article focuses on the narratives of 20 women living with HIV; five of them were pregnant during the pandemic. Two HIV-positive women cannot join the the last FGD due to severe health conditions.

Research Method

Methods utilised in this project include a series of focus group discussions (FGDs), go-along (informal) interviews, and visual forms (Figure 1, 2). Each meeting was about 30-60 minutes, and there were repeat meetings (between two and five times). The first author conducted a series of focus group discussions (FGDs), informal interviews and virtual FGDs or interviews. The first author discussed the lists of interviews and FGDs with the second author and NGO workers. The first author conducted the pilot project for women NGO workers related to HIV to avoid the stigma attached. Digital audio recorders are used to record all data or field notes were also undertaken. The first author obtained verbal or written informed consent for inclusion into the study, including informed consent for the publication of this material. Only participants were present

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3 during the data collection phases. Transcripts were not returned to participants and this
4 was made clear during initial rapport building exercise. The logistics of this were too
5 difficult and low literacy skills meant more suitable ways of follow-up were preferred
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7 (e.g. post-interview WhatsApp chats).
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11 [Insert Figure 1: [Data Collection Cycle](#)]
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14 [Insert Figure 2: Visual outcomes of participants' action during research process]
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16 FGDs are particularly useful in gaining participant ideas and aspirations that might not
17 have been accessible without group interaction (15). Interviews were undertaken
18 minutes in cases where a participant's preference over a group discussion was held in
19 outdoor areas, such as a restaurant, visiting a house with open doors and windows, and
20 wearing masks (16). In addition, participatory visual methods were used during a series
21 of FGDs and interviews. Participatory visual methods are considered modes of inquiry,
22 production, and representation in the co-creation of knowledge (17). Alternatively,
23 virtual FGD, interview, and participatory visual methods were chosen if there was
24 COVID-19 restriction and the participants chose to do it.
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32 33 Data analysis 34

35 Narratives from interviews, group discussions, and visual outcomes were transcribed
36 verbatim in Bahasa Indonesia. Field notes were recorded in both Bahasa Indonesia, and
37 English was sent daily during fieldwork to the second author. The interpretations of the
38 women's voices and presentations were coded in their original language by the first
39 author using manual coding (18). Regular chatting through private Facebook
40 messengers was conducted between the authors to discuss emerging themes,
41 categorisation, and links between codes and meanings, enhance data interpretation and
42 ensure consistency. Both authors developed themes from the coding before translating
43 relevant quotes into English. Four main themes emerged around the experiences of
44 women living with HIV during the pandemic:
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- 52 1. HIV stigma
 - 53 2. HIV-positive women's resilience in dealing HIV discrimination
 - 54 3. Non-disclosure of HIV status in health settings
 - 55 4. Fighting HIV stigma and discrimination
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4. Respondent's characteristics: HIV-positive women

In total, 20 women living with HIV contributed to this study. They were aged 21 to 49 years. Six were widowed and 14 were married. Most of the 20 women living with HIV had disclosed their HIV status to their family, including their parents and siblings. However, only four of the 20 women had disclosed their HIV status to health workers in non HIV-health centres (such as VCT centre), either in private practice or at the public health centre (*puskemas*). Of the four who were brave enough to open their HIV status, they did so to get Antiretroviral (ARV) medicine or give birth to their baby in PMTCT services (Table 1).

[Insert Table 1: [Respondent's characteristics: HIV-positive women](#)]

During the first year (2020) of the COVID-19 pandemic in Indonesia, we found that stigma attached to HIV was doubled for women who sought health services during delivery or for therapy for other diseases. Our study found the women lose either way. If women did not disclose that they had HIV, they could not get proper treatment for their HIV. However, we also found that if women did disclose their HIV status, medical professionals would refuse to treat them for fear of contracting HIV. Below we share some of the stories we heard.

5. HIV Stigma

Our research revealed many perceptions about HIV and married women, all of which were negative and included: 1. Women living with HIV have a *penyakit kotor* (dirty diseases); 2. It was a disease women got if they had sex outside marriage and changed partners frequently (*gonta ganti pasangan*); 3) it was a sign of an unfaithful wife (*wanita tidak setia pada pasangan*); 4). They were despicable women (*perempuan hina*); 5). That good wives and mothers could not get HIV, so if a woman had HIV, she would be a bad/naughty woman (*perempuan tidak benar/wanita nakal*) (Figure 3). Sadly these negatives notions are widespread in the community and normalised in health settings (6).

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3 [Insert Figure 3: [Label on HIV-positive women](#)]
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6 HIV-positive mothers expressed feelings of being stigmatised as unfair as they felt they
7 were good mothers, mothers with a good manner (*perempuan berakhlak baik*), and
8 breadwinner. HIV-positive mothers defined stigma as meaning bullying (*ngatoi*),
9 insulting (*menghina*), isolating (*mengucilkan*), being fearful (*takut*), dan terrible
10 (*mengerikan*) (see Figure 4). Sadly, the women who disclose their HIV status to their
11 family or health workers may deal with discrimination, including their children.
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17 My children felt the same [stigma] though they are free of HIV. Stigma was
18 hurtful not only for me but also for my children. Stigma was very painful for
19 my children. We lived separately from our parent's house, were mocked,
20 insulted. It hurts a lot (Mila, an HIV-positive mother, and widow with three
21 children).
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26 [Insert Figure 4: HIV and COVID-19 related stigma intersecting for mothers living with
27 HIV from themselves (*diri sendiri*), family (*keluarga*), neighbour (*tetangga*), society
28 (*masyarakat*), health (*tenaga kesehatan*) and friends (*teman*).]
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32 One women we spoke to revealed (see Figure 5):
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34 We know there are other risk factors to get infected with HIV, such
35 as a good woman may access beauty therapy where they use non-
36 sterile equipment. However, the negative stigma was always there,
37 before women with HIV explain about her experience. HIV-positive
38 mothers may look like a good and pious mother, the reality she may
39 not (Rima, a working woman, free of HIV).
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45 [Insert Figure 5: Perception of a good mothers and wives living with HIV]
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47 Interestingly, with the information to fight stigma related to HIV, HIV stigma might be
48 reduced, particularly during the pandemic. Health workers focus on COVID-19
49 screening in health services, not HIV. Therefore, there might be miss-opportunities to
50 diagnose earlier HIV during the pandemic as every woman is at risk of HIV, including
51 a good and pious mother (2,5).
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56 There has been an overwhelming stigma for people who contract COVID-19, and this
57 stigma doubles for women living with HIV. The mode of HIV transmission might be
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3 contributing to moral judgment and negative perception of people living with HIV. HIV
4 was related to the genital, reproductive system, and sexual activity, while COVID-19
5 was transmitted through air, not sexual activity.
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9 HIV stigma is always negative as mode of HIV transmission relate to
10 reproduction and the genital area, so the stigma is negative. COVID-
11 19 has different mode of transmission, the virus spread through air,
12 not from fluids or sexual activity (FGD with group of HIV-positive
13 women).
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19 Though stigma relating to COVID-19 does not have the moral judgment attached to it,
20 like HIV, our study highlights that women living with HIV suffer from a double burden
21 of stigma when they try to access healthcare during this pandemic. The following
22 studies explored the stigma. Nika was treated in isolation for COVID-19 due to her
23 severe cough, and Yuni was judged to be COVID-19. Yuni always complains about
24 unfair treatment for her baby during her delivery, though her COVID-19 showed
25 negative.
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32 **6. Yana's story: "It is better to treat COVID-19 patients than an HIV-positive**
33 **patient"**
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36 *I came to the hospital to give birth*

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38 *I told them I have B20 (a medical term for HIV)*

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40 *But I was considered a badly behaved woman*

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42 *Who was going to infect health workers?*

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44 *Nevertheless, I was a good mother.*

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46 *And I was afraid of infecting my baby and the health workers with HIV*

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48 *I was stigmatised*

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50 *I did not get any respectful antenatal service*

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52 *I was accused of being an irresponsible mother and having multiple [sexual] partners*

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54 *I am the head of the family and the breadwinner*

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56 *Alhamdulillah, I thank God*
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My three children are HIV-negative

The above letter is sent to the first author from Yana (via WhatsApp), a 25-year-old mother living with HIV in Indonesia for health workers, in March 2021. The letter reflected her journey, her struggle, and life accessing antenatal care for her delivery during the pandemic. FPAR facilitated an empowerment process for Yana to analyse and write about her situation and to share her story with me.

She recounted that in December 2020 that was rushed to the 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. Yana also knew she needed to disclose her HIV status to protect the doctors 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 pushed her and asked: “why didn’t you tell us at the first stage?” A midwife added, “For me, I prefer to treat COVID-19 patients than HIV-patients”. Another health worker said to Yana:

If you were tested for COVID-19, the result is more likely positive. I said, no, I am not COVID-19 positive; I am healthy. Please, do not judge (pray, *mendoakan*) for me to have COVID-19. If I got infected with COVID-19, you would get sick too. Then, the health worker was silent.

Yana complained to people at the hospital that it was unfair to treat her like this. Finally, Yana received the proper antenatal care treatment but only after she insisted on seeing another doctor.-(c.f. (9)).

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3 **7. Nika's story: Is it better to disclose your HIV status or not during the COVID-**
4 **19 Pandemic?**
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7 In July 2020, 33-year old Nika suffered from appendicitis and needed to undergo
8 surgery. She decided not to disclose her HIV status because she worried that she would
9 not receive proper and respectful care. Nika believes that HIV-related stigma has
10 become worse during the pandemic. Based on her experience, she revealed that every
11 patient entering the hospital was suspected of having COVID-19 and if a patient then
12 disclosed their HIV status that would face a difficult time getting treated. She recounts
13 that:
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20 [In July 2020] Yes, I seek health services in a public hospital; I do
21 not disclose my HIV status. There is a strong stigma of being an HIV-
22 positive mother; I cannot imagine if I disclose my HIV status. I do
23 not want to open my HIV status. You know why? I access third-class
24 facilities (there are 5-8 patients in a room), stigma is strong during
25 the COVID-19 pandemic (every patient was suspected of having
26 COVID-19). I am alone during my hospitalisation; no companion
27 (from my family) was allowed. If I disclosed my HIV status, people
28 would not treat me, they will run from me, and no one will take care
29 of me, and no one will inject the medicine for me. In my observation,
30 health workers are more afraid of HIV than COVID-19.
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40 In February 2021, Nika was sick again and was rushed to hospital. She was coughing
41 and had difficulty breathing. She was quickly diagnosed as having COVID-19 and was
42 treated in an isolation room for 10 days. Nika expressed her experiences through her
43 diary notes (see below). Sadly, Nika's son informed the first author through WhatsApp
44 that Nika passed away in July 2021 with diagnoses of a suspected COVID-19.
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50 Saturday, 6 February 2021. In the morning, I was very weak and
51 asked my parent to take me to the hospital. When I arrived at the
52 hospital, I visited the emergency room straight away. I was checked
53 and diagnosed with COVID-19, even though I had not been tested for
54 COVID-19. My shortness of breath and severe coughing were similar
55 to COVID-19 symptoms [so the doctors assumed I had it]. I was
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3 treated in an isolation room along with one other COVID-19 patient.
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5 No health workers treat me from the morning to the afternoon. I felt
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7 so weak and had difficulty breathing. At 2 pm, a nurse took my blood
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9 and did an infusion, and gave me oxygen. At 9 pm, I was moved to
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11 another isolation room where I was by myself. The room was clean,
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13 and the doctors and nurses were friendly. At midnight, an X-ray was
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15 undertaken. I was in the isolation room for ten days to recover my
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17 health; then I was moved to another room after the COVID-19 result
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19 showed negative (Nika).

20 **8. Tiki, Nur and Oneng: Fighting COVID-19 stigma to ensure the** 21 **health of themselves and their HIV-positive children**

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23
24 During the pandemic, people who need hospitalisation were often reluctant to seek
25
26 health services because of rumors that every person entering a hospital would be
27
28 diagnosed with COVID-19 (Author A et al., 2021). This section focuses on three
29
30 different stories of HIV-positive women accessing health services during the first year
31
32 of the COVID-19 pandemic. While Tiki and Nur were able to ensure that their HIV-
33
34 positive children were provided with the proper care and treatment, Oneng sadly passed
35
36 away due to late hospitalisation. Oneng left behind six children. Nur was able to seek
37
38 treatment to prevent her baby from contracting HIV.

39 Tiki, 33-years-old, decided to visit a public hospital in her village as her son lives with
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41 HIV; he is five years old. During the pandemic, he suffered from a tumor on his neck.
42
43 Tiki's wrote in her diary that she shared with us:
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45 Dear my story. My days, my life is not easy. I open my eyes at
46
47 midnight, my heart beating, and sometimes I want to give up. Many
48
49 friends ask about my son's disease, [they have] many questions, they
50
51 may show they care, [but] I only answered that my son suffers from
52
53 a small tumour on his neck. I know it is an opportunistic infection
54
55 from his low immunity due to HIV. However, I am sure God (Allah)
56
57 knows I can pass this trial, and I know it is not easy to live with HIV
58
59 at a young age with my youngest son (Tiki).
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3 Initially, she was afraid of visiting the hospital due to rumours of COVID-19 in
4 hospitals and that everyone would be tested for COVID-19. After an online consultation
5 with the doctor in VCT centre, the doctor asked her to bring her son to the hospital on
6 February 2021. It took four hours from her village for her to get there. Tiki noted that
7 there was no need to feel afraid of visiting hospitals and she fought against the rumours
8 surrounding COVID-19.
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15 I feel the healthcare centre is more humanist during the pandemic.
16 The health workers treated my son very well, and they were full of
17 smiles before and after his operation. The doctor did not discuss
18 COVID-19 or COVID-19 tests. The health workers focused on my
19 child's health condition, and I feel relief (Tiki).
20

21 In November 2020, Nur, 38-years-old, and into her second pregnancy, needed to treat
22 her malnourished daughter, Ana (18 months). She needs to stay for a week in a public
23 hospital. She recalled that a doctor called Nur in the emergency room in a public
24 hospital, and as it was a crowded room, she disclosed Nur's child's HIV status with a
25 low tone of voice in the corner of the room. It was like a 'thunderstorms' for Nur. Then,
26 one week after her daughter's hospitalisation, Nur's husband was treated in the ICU
27 room due to a complication of Tuberculosis and HIV, and Nur needed to prepare her
28 caesarean section to minimize HIV risk to her second baby. Nur was aware of a doctor
29 in a private hospital that was recommended.
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38 In the private hospital, my daughter had been treated for her
39 malnourished condition. One nurse explained that the specialist,
40 doctor Nando (all names are pseudonyms) specialised in her
41 daughter's condition but had other work and could not treat my
42 daughter. Therefore, the hospital decided to refer my daughter to the
43 public hospital. After arriving in the emergency room in the public
44 hospital (at 9.30 am), the doctor explained the HIV status of my
45 daughter. I was shocked to learn that she was infected with HIV. I
46 was just aware that the doctor, who was mentioned in the private
47 hospital, is a doctor who is specialised in treating HIV-positive
48 patients (Nur).
49
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51 From Tiki and Nur's experience, caring for their HIV-positive children and being brave
52 enough to access health services for their children suggests that they wanted to protect
53 their children from any harm. Therefore, they fight against HIV stigma by accessing
54 help for their children's health. By sharing their story, they hope that it would reduce
55 stigma for both HIV-positive mothers and children. However, stigma related to HIV
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3 surrounding health services might contribute to late therapy for HIV-positive children
4 and mothers, like the following story of Oneng.

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6
7 Oneng, 44-years-old, was incredibly sick between March 2020 and December 2020 due
8 to HIV. The doctor in VCT centres changes her Antiretroviral medicines, and she
9 suffered from side effects. However, because she was afraid of visiting the hospital and
10 contracting COVID-19, she postponed her hospital visit until February 2021. Before
11 February, she only used medicines she brought from roadside stalls (warung) and
12 pharmacies and sometimes after visiting her closest doctor.

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19 My doctor asked me to visit the hospital for hospitalisation. When I
20 ask whether we needed to get a COVID-19 test in the hospital; he
21 said yes. It made me feel scared that I would not recover. I felt very
22 stressed. I decided to treat myself at home rather than going to
23 hospital, where I would have to get a COVID-19 test (Oneng)

24
25
26 Oneng reflected on her experiences of trying to access antiretroviral therapy (ARV)
27 monthly. She said that the HIV-service was different during the Pandemic and that she
28 could not consult with the specialist HIV doctor and that there was such distance from
29 patient and doctor in the HIV services. Oneng explained that before the COVID-19
30 Pandemic, the doctor still checked her chest and blood pressure and close contact during
31 consultation. However, doctors would only ask about her symptoms from a distance
32 and give her prescriptions and advice during Pandemic. She felt disappointed and
33 heartbroken. Though she looked faint and weak, she decided not to talk about her severe
34 condition during her visit to get ARV medicines.

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42 Finally, Oneng visited the hospital in the last minutes with support from NGO workers.
43 After feeling better, she was treated at home. Sadly, the following week, she passed
44 away. Oneng's daughter shared her mother's story when the first author visited after
45 Oneng's funeral in mid-2021:

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52 We are happy my single mother recovered before the end of the
53 fasting celebration. However, she was faint and felt weak. There were
54 too many medicines she took. We decided to bring my mother to the
55 hospital again, but in the emergency room, my mother passed away.
56 Our thought is about my little sister who is HIV-positive too. My
57 mother (Oneng) has taught us how to take ARV medicines in the
58 hospital for my sister. We are orphans now (Oneng's first daughter).

9. Discussion

HIV-positive women are aware that they will face stigma from family, health workers, friends, and neighbours. This article highlights how HIV-positive women are negatively labeled by society and health services (Figure 6). The normalization of institutional stigma and discrimination is rampant in Indonesia's health setting for women living with HIV, including disclosing HIV's patient status and low priority of health services for HIV-positive women (6,19). Therefore, they need to consider to whom they disclose their HIV status. Consequently, HIV-related stigma is considered the main factor behind low uptake of and poor adherence to HIV prevention and treatment services (20).

[Figure 6: HIV-positive resilience in fighting HIV and COVID-19 stigma during Pandemic]

During the pandemic, HIV-positive women needed to brave enough to seek health services while most people may avoid seeking health services (See Figure 6). The prospect of every patient being diagnosed with COVID-19 was rampant in the community into 2021 (9). We argue that the women may lose either way, through disclosing or not disclosing their HIV status in a health setting.

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. As we can see from Yana's story, it is necessary to have a brave and confident voice like hers, and for Oneng to seek NGO workers' help, 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. Of course, the number of those who can do this remains very small, as most people choose to remain silent because they are powerless.

As a result, according to Park and Aggleton (2003), understanding stigma requires consideration of the intersectional influences of the broader social, cultural, and economic factors that structure stigma beyond the level of the individuals (21). HIV-

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3 positive women need to be resilient, drawing on support from their families, supportive
4 health workers to access health services for the sake of their children and their health.
5 In addition, stigmatised groups, like women living with HIV, may avoid COVID-19
6 testing, disclose HIV status in health services, and avoid accessing health services
7 during their sickness. Health services need to work with peer supports for HIV-positive
8 women (Non-governmental organisation related to HIV) to provide a safe environment
9 to get the right health services (22).

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11
12 At the policymakers level, the Indonesian government needs to create supportive health
13 systems, including peer education for health workers who can provide safety and
14 confidentiality for HIV-positive women (6,9). Therefore, the women feel safe, feel
15 protected, and appreciated as good and religious mothers and wives to reduce the
16 institutionalized stigma in society. In this context, we suggest that the Ministry of
17 Health, in collaboration with the Ministry of Education, needs to include sexual and
18 reproductive health rights and gender equality, particularly for HIV-positive women, in
19 the health curriculum.

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22 The following is a poem titled "Corona virus and HIV please go away" developed by
23 an HIV-positive mother who gets infected with HIV from her husband, and now she
24 raised a free HIV daughter alone after her husband's death.

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27 Motherland....

28
29
30 I know the sky is cloudy and sad because of COVID-19 and HIV

31
32
33 Both are deadly

34
35
36 But they transmitted in different ways

37
38
39 Motherland...

40
41
42 It doesn't feel it's been more than a year that COVID-19 exists

43
44
45 It doesn't feel HIV already exists on this earth for a long time

46
47
48 Go away COVID-19

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51 Go away HIV

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54 Don't stay in our hearts and minds

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56
57 Motherland

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59
60 Please be at peace with us in this time of the pandemic

Like HIV, be at peace with the world

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2
3 Although painful, discrimination is still attached COVID-19...
4

5 Please be at peace with health protocols
6

7 Motherland...
8

9 Never be afraid of COVID-19 and HIV
10

11 Let's test ourselves
12

13 To ensure the health of our children and our family
14

15 Before it's too late
16

17 Let's do the test right now
18

19 Don't postpone it
20

21 **10. Conclusion**

22
23 In this paper, we have explored how women are living with HIV access medical care
24 during pandemic times. We revealed that women face difficult decisions, especially
25 regarding whether to disclose their HIV status or not. Given the enduring stigma of
26 living with HIV, many women are rightly fearful of revealing their status as they know
27 the care they receive will be jeopardised. Medical professionals are still afraid of HIV
28 in Indonesia because they lack proper education around transmission. COVID-19 has
29 given personal medical excuses not to treat women with HIV because health care
30 resources are so stretched. But many women are bravely disclosing their status and
31 demanding they receive proper health care, especially when they are pregnant and have
32 young children
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42 We hope that this article shows that it is important to listen to women's stories,
43 especially around HIV and COVID-19. While COVID-19 patients need to be
44 prioritised this should not be at the expense of women living with HIV. Governments
45 need to ensure that women living with HIV, especially mothers, can access the
46 healthcare they need for themselves and their children. Indeed for two mothers we
47 spoke to, they received good HIV healthcare for their children and as such, it is possible
48 for some, yet not for all in Indonesia to access HIV care.
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12. Ethical approval

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

13. An author contribution

The first and second authors designed the research protocol, data analysis and writing of the manuscript. The first author was responsible for transcribing the interviews, FGDs and visual outcomes. The second author assisted in translating quotations into English.

14. Conflict of Interest

None to declare

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