To get tested or not: A project to reduce stigma around COVID-19 and HIV testing in Indonesia

Final Report

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Sharyn Graham Davies is Director of the Herb Feith Indonesia Engagement Centre and Associate Professor in the School of Languages, Literatures, Cultures and Linguistics at Monash University in Melbourne, Australia. She received her PhD from the University of Western Australia (Anthropology and Asian Studies) and prior to her appointment at Monash was at Auckland University of Technology (AUT) in New Zealand. Sharyn has held visiting fellowships at Cambridge, Yale, Sydney, Peking and Airlangga universities, and has been awarded Fulbright, Leverhulme and Marsden funding. Sharyn is recognised internationally as an expert in the field of Indonesian Studies and for her contributions to the study of gender, sexuality, policing, social media, and moral surveillance.

Chapter 1. Introduction

1. Project objectives

The objective of this project is to reduce the stigma associated with getting tested for COVID-19 and HIV. While testing facilities are available, the stigma associated with getting tested prevents many people from getting a test. In addition, the COVID-19 Vaccine hesitancy was also explored in this project.

Indonesia has provided opportunities for citizens to get tested for diseases such as COVID-19 and HIV. Unfortunately, though, the stigma surrounding getting tested, and getting a positive test result, means many people simply do not get tested. The stigma also attach on COVID-19 vaccination, that lead to vaccine hesitancy among Indonesia. This project will develop strategies for health care practitioners and policy makers to implement to enable people to get tested without stigma, or at least it will provide strategies to reduce stigma surrounding testing and COVID-19 vaccines. We will focus specifically on women as they wear the brunt of stigma in Indonesian society.

While the scope of this project is modest, its effectiveness will be seen in an increase in the number of people getting tested, and in fewer people refusing tests because of concerns around stigma.

2. Project rationale

The proposed project is important because without regular testing illnessses such as COVID19 and HIV can spread unchecked through communities. But because of the stigma associated with getting tested, many people do not get tested (Najmah, Davies, Andajani, 2020). This project addresses the issue of stigma associated with stopping people getting tested; and second by developing strategies that can be implemented to ensure that stigma does not prevent people getting tested for COVID-19, HIV or other diseases as well as accesssing COVID-19 vaccines.

3. Methodology

Our project was guided by a Feminist Participatory Action Research (FPAR) framework. FPAR enabled Najmah and Davies 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-middle income families. We applied FPAR to explore women's diverse experiences of pregnant women accessing antenatal care, including accessing COVID-19 and HIV tests during the COVID-19 pandemic. We conducted a series of FGDs and go-along interviews with 20 HIV-positive women, and 20 women who have felt stigma in being tested for COVID-19 in Palembang, South Sumatra. From 40 women, 15 women were pregnant during pandemic. Furthermore, 10 health workers were interviewed as a part of triangulation process.

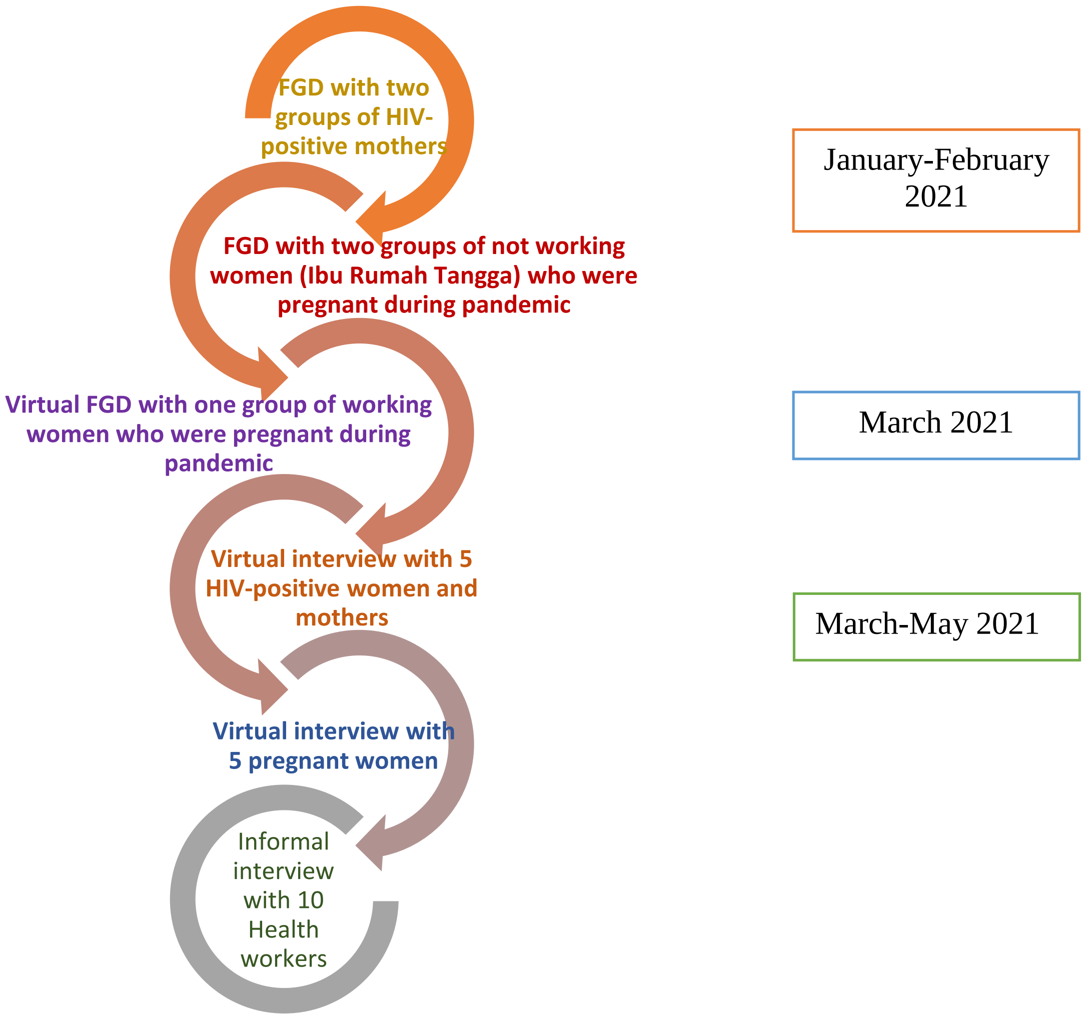

Figure 1. Data collection Cycle

Methods utilised in this project includes a series of focus group discussions (FGDs), go-along (informal) and interviews, and visual methods. FGDs are particularly useful in gaining participant ideas and aspirations that might not have been accessible without group interaction. Interviews were undertaken in cases where it is a participant's preference over a group discussion and were held in outdoor areas, such as restaurant, visiting a house with open door and window, as well as wearing masks. 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. Alternatively, virtual FGD, interview and participatory visual methods were chosen if there is COVID-19 restriction and the participants choose to do it.

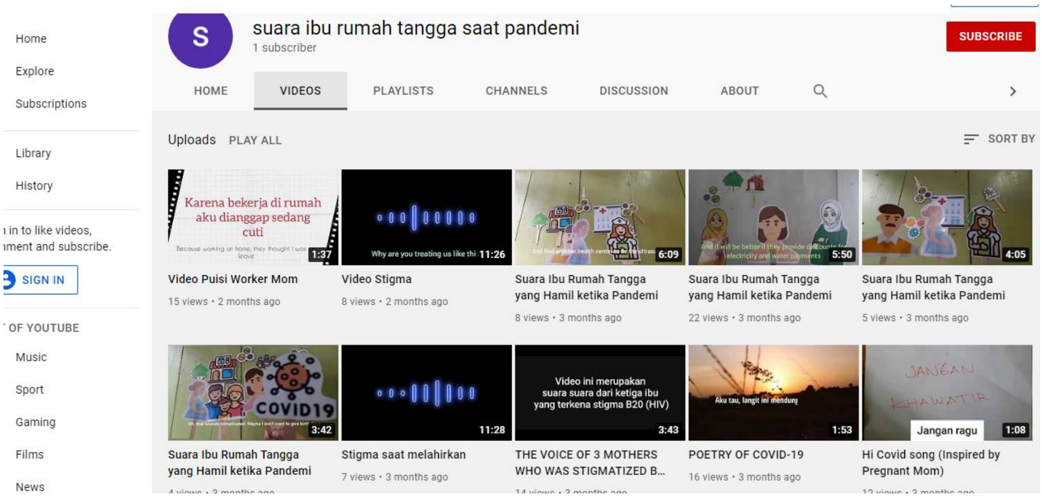

Figure 2. Visual outcomes of participants'action during research process

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

In these ways the proposed project will address the issue of women not getting tested for COVID-19 or HIV because we will understand the ways in which stigma prevents them from getting tested, and in collaboration with the women we will develop strategies to overcome these difficulties. The additional information about COVID-19 vaccines hesistancy was also explored in this research.

4. Research setting

Our research site is located in Palembang, South Sumatra, Indonesia. Palembang is bordered by the Banyuasin Regency on the North, East, and West sides, and Muara Enim and Ogan Ilir Regency to the south. The area is about 40,061 km^2 with a total population of 1.5 million people in 2015. Palembang is divided into two main areas by the Musi River: Seberang Ilir and Seberang Ulu. There are 18 districts (*kecamatan*) in Palembang with 107 sub-districts (*kelurahan*) in all *kecamatan.*

The average monthly income of a Palembang worker is approximately Rp 1.2 million ($85 US),[1] with about 200,000 or 11 percent of the of the population living on less than half of that, at RP 480,000, or about $35 US per month (Statistics of Palembang, 2018). While men and women over 15 years old have similar access to education, unpaid domestic work in the home is still largely undertaken by women; about 92 percent compared to about eight percent of men (Statistics of Palembang, 2018c).

Palembang has 147 clinics, hospitals and public or community health centres. However, the ratio of health workers to population is low, at about 0.5 per 1000 population or about 2000 health workers for 1.5 million people. In terms of ante-natal visits, the majority of women (about 90%) in 2017 to 2020, made at least four visits. Contraceptive methods among married spouses are mainly progesterone injections, the pill, and implants (Statistics of Palembang, 2018b).

5. Defining Gender Roles in Indonesia

This section focusses on two interrelated domains of Indonesia's gender expectations which shape women's lives: 1) Heterosexual marriage embedded in Indonesian government policies and law, and 2) patriarchal Indonesian Islamic values.

Expectations of Women in Sumatra, Indonesia

> I am familiar with questions such as: "when will you get married?" - a question I was repeatedly asked after I graduated with my bachelor's degree aged 24 years and my master's degree at the age of 27. Soon after, queries turned to "when will you have your first child?" (immediately after my marriage), and then, "when will you have another child for a boy?" (after having two daughters). When I was pregnant for the third time, my friends and families said, "we hope you will have a boy". No one questioned me further after my third child, a son, was born during my doctoral study. Then, the common response was, "finally, *Alhamdulilah* (thank God) you have a son" (Najmah's Research Journal, 2018)

The Indonesian government's promotion of monogamous, registered heterosexual marriage is embedded in government policies. Based on the Indonesian

[1] Ibid.

Marriage Laws no 1 in 1974, a man is able to marry one wife; and a wife marries one husband[2] (GoI, 1945, 1974).

It is claimed that these aims are to protect women's and children's rights within the marriage from so called unfair marital practices, resulting in women's vulnerability and neglected children (GoI, 1945, 1974; Nurmila, 2009, 2016). The Indonesian government set out the wives' and husbands' roles and responsibilities, promoting equal rights for married people (for example, parents are obliged to rear and educate their children[3]).

Within this legislation, the Indonesian government separates roles for wives and husbands which are delineated into the domestic and public spheres. For example, women's domestic roles are emphasised, particularly their role as housewives (article 31, section 3) and household managers (article 34, section 2). These are constructed as primary, before their roles and participation in the public domain (GoI, 1974).

Despite these definitions, married women's roles now expand far beyond the household, to advancing their education and working outside the home (Damar, 2014; Nurmila, 2016). Even with many women having careers, it is not uncommon to hear career women expressing the government narrative, stating that their primary commitment is always to their husband and children, before work or study (see Andajani, et. al). A commitment that places women in a balancing act, one that masks and undermines their new economic roles, while reinforcing traditional gender roles in Indonesia. The result is often placing women in a state of conflicted and potentially harmful priorities (see Andajani, et.al. (2016); Nurmila (2016)). For those women who work in the public sphere, the workaround is to pay other women as house cleaners or child-minders, for couples who can afford these services (Damar, 2014; Nurmila, 2016; Suryakusuma, 2011).

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[2] See Chapter I, verse 1, 2 and d 3 in UU No 1 in 1974.

[3] Article 45, Section 10 in The Indonesian Marriage Law 1973.

These conflicting pressures are shown in a poem from one of our participants who expressed their feelings regarding their challenges to working, raising children, supporting husbands, and being pregnant during the COVID-19 pandemic:

Poem: Oleh Ibu Winda, a Working Mom.

I just realised the joy of life
When covid was around
It turned out that
Everyone was afraid of sickness and death
I just realised the pleasure of working
When keeping distance is a key
So that everyone can avoid harm
I just realised the pleasure with family
When the policy of stay at home have to be enforced
Because everyone is busy taking care of themselves
I just realized the joy of being a mother
When I spent my 24 hours looking after my child
Because I don't want him to know how worried am I
I just realised the joy of being a wife
Because working at home, they thought I was on leave
Then, finally I asked myself "is it fair?"
I just realised the pleasure of eating a bowl of hot noodles
Because I am a mother and a lecturer at the same time
Make me to the point of insanity
But in the end
I have to keep in my mind His great blessings
I am a mother and a worker who gave birth during the pandemic

The above poem highlights the contradictions within competing narratives, which may be seen in the daily lives of many women who work in the informal sector, who are the primary earner for their family. Like the first and second authors' mothers, their husbands may not have regular incomes.[4] But in government statistical categories, these women are still defined as *ibu rumah tangga* (housewives), despite working and earning enough money to meet the household's needs (Dini, 2019; Najmah, 2019, 2021).

6. Sumatra Women and Islam

Islam purports to inform every aspect of a woman's sexual life, particularly motherhood and sexual pleasure, within the parameters of heterosexual marriage. Motherhood is a prestigious and high-status role in Islam as the *Hadith*[5] states: "paradise lies at the feet of the mother" (Pappano & Olwan, 2016, p. 1). A Muslim woman is expected to observe and incorporate rituals and guidelines regarding maternal beliefs and obligations into her childbearing life (Ayubi, 2019; Ibrahim & Songwathana, 2010; Isgandarova, 2016). All elements within motherhood and marriage, for example, breastfeeding, pregnancy, obedience to her husband, and mutual sexual fulfilment, are considered as worship of God (*Allah)* and obedience to His Messenger (the Prophet Muhammad) (Isgandarova, 2016).

Religious expectations on Muslim women around marriage and motherhood are defined by morality and heterosexual gender normativity. Those who fall outside the practice of heterosexual morality, are seen as 'other' and may lose face or be made to feel ashamed or ostracised as outsiders. In the past, those who have extramarital affairs may be sanctioned (*adat punishmeht).* Such punishments may require them to pay a sum of money, sacrifice buffalo, to leave their villages and be isolated from their

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[4] DINI, D. (2015). *Factors affecting labor participation of married women in informal sector in west sumatra* (Doctoral dissertation, UPT. Perpustakaan Unand). http://scholar.unand.ac.id/619/Intersections:'Believe it or not, it's COVID-19': Family Perceptions of COVID-19 in Palembang, Indonesia (anu.edu.au) Najmah, 2019, dissertation.

[5] Hadith is the words, actions, and silent approval of the Islamic Prophet Muhammad, messenger of God in Islam. This hadith "Paradise lies at the feet of the mother" is narrated by Ahmad Nasai, cited in Pappano and Olwan, 2016, p 1. Another hadith that support this messenger's words is narrated by Bukhari Muslim, that said A man came to the Prophet and said, 'O Messenger of God! Who among the people is the worthiest of my good companionship? The Prophet said: Your mother. The man said, 'Then who?' The Prophet said: Then your mother. The man further asked, 'Then who?' The Prophet said: Then your mother. The man asked again, 'Then who?' The Prophet said: Then your father" (Bukhari, n.d.).

community, or even become a slave (*bersih desa)* (Marsden, 1788). Even today, these punishments may still be applied at the village level, painting women as objects of gossip, who are considered immoral (Bennett, 2005; Davies, 2015; Nurmila, 2016; Najmah, 2019). Pressure to conform to publicly defined heteronormativity may also be brought to bear on the wider family of the individual who engages in sex outside marriage, who risk bringing shame and bad luck (Blackburn et al., 2008).

The heteronormative definition of gender roles by the Indonesian government, and within Islam, negatively intersects with government responses to COVID-19. These are shown in the following section.

7. Structure of the report

This report is structured into six chapters.

Introduction (Chapter 1)

In this chapter, we introduced the project objectives and rationale, identified the research methodology of the study, and outlined the report structure. We also explore gender roles in Indonesia and Sumatra women and Islam.

Indonesian context: COVID-19 denials in Indonesia (Chapter 2)

Chapter 3 provide a critical examination of COVID-19 denials in the Indonesian context. It synthesises four main themes: downplayin the virus, seeds of mistrust, loal contexts and mixed messages. We argue that the lack of a unified message is compounded by low digital literacy rates across socioeconomic classes.

Findings (Chapters 3, 4, 5 and 6)

Chapter 3 through 6 present key empirical findings from the field work. The research findings are presented in three chapters. The first chapter is ‘Fears of pregnant women to seek antenatal care during the pandemic: Disrupted routine maternity in South Sumatra, Indonesia’; the second chapter is ‘Endless stigma of HIV for women with HIV during COVID-19 Pandemic’, and the third chapter is ‘What’s behind COVID-19 vaccine hesistancy in Indonesia?’. The final chapter is Disclosing HIV Status during Indonesia’s COVID-19 Pandemic: Challenges faced by mothers.

Chapter 2. Indonesia context: COVID-19 denial in Indonesia[6]

Mixed messaging from government about COVID-19 has left rumours and competing narratives to fill the information void, fuelling mistrust

Figure 3. COVID-19 denial in Indonesia in Insider Indonesia

The World Health Organisation declared COVID-19 a global health pandemic in early 2020, with all countries affected to a greater or lesser extent. As of late June 2021, Indonesia had reported 1.9 million cases and over 54,000 deaths. However, these official figures should be treated with caution, if not outright scepticism, as COVID-19 testing is limited in Indonesia, and significant health facility disparities exist across the various municipalities.

Indonesia's testing rate is one of the lowest in the world, with less than 50 people per 1000 being tested (as of late June 2021). A key reason for low testing rates is that the test is not free unless you are symptomatic and can access a particular clinic; otherwise

[6] This article was published in Inside Indonesia, 21 June 2021, collaberated with Kusnan, Sari Andajani, Sharyn Graham Davies and Tom Graham Davies. Retrieved in https://www.insideindonesia.org/covid-19-denial-in-indonesia

the cost is prohibitive for many. Indonesia's reported cases of COVID-19 must, therefore, be significantly higher than official figures suggest. Underreporting is thus of significant concern given that on 18 June 2021, Indonesia reported over 12,000 new cases.

Like many other countries, the Indonesian government has issued a policy to control and prevent the spread of COVID-19 in the form of Regulation Number 9 of 2020, concerning large-scale social restrictions, known as Pembatasan Sosial Berskala Besar (PSBB). This policy has proven to be only partially effective in slowing the increase in cases of COVID-19 infection, and the implementation and enforcement of PSBB varies starkly across regions. The government is now focused on its vaccination program, not on COVID-19 testing.

The impact of the pandemic and associated government-imposed large-scale social restrictions on Indonesia's economy can be described as catastrophic. The *East Asia Forum* reports that in the last three quarters of 2020, Indonesia's growth rate averaged less than negative 4 percent. This negative growth rate caused about two million more Indonesians to fall below the poverty line and unemployment to rise to around 7.1 percent (as of August 2020).

Unlike some of its richer neighbors, Indonesia can ill afford these impacts, and the government has been under constant pressure, particularly from business owners, to relax large-scale social restrictions. As a result, a more relaxed approach to COVID-19 is influencing perceptions of COVID-19 among the general population. Currently, central government has announced a further preventive approach called 'Pemberlakuan Pembatasan Kegiatan Masyarakat (PPKM) Mikro' or 'Micro-Scale Society Activities Restriction' by involving small districts, including kelurahan (villages) and kecamatan (sub-districts) and police and Indonesian military.

Downplaying the virus

The Indonesian government prioritised the economy (rather than health) in its response to COVID-19. This decision then led to the government and its media outlets presenting information downplaying the harms of COVID-19. It should be noted at this juncture that the decision to focus on the economy was, at least in part, due to capacity limitations of the government. Through its social media and online media platforms, in particular, the government has led the notion that COVID-19 is not particularly harmful to health.

In February and March 2020, the then Minister for Health Terawan Agus Putranto, made a series of controversial statements, that experts pointed out at the time underestimated the dangers of coronavirus. Some of Terawan's statements included 'we are not afraid of diptheria; of course we are not afraid of COVID-19' ('Difteri saja kita tidak takut apalagi korona'); 'Flu is more dangerous than corona virus' ('Flu lebih berbahaya daripada virus korona'); and 'masks are only for sick people' ('Masker itu untuk orang sakit'). As recently as October 2020, then still Minister of Health, Terawan, was reported to support the use of herbal medicines to treat COVID-19 and endorsed the Ministry of Health in its policy of using them in healthcare facilities. In late December 2020, Terawan was removed from his position as Minister in a cabinet re-shuffle, and replaced by Budi Gunadi Sadikin.

It should be noted that we are aware that analysing and presenting the above messages paints a picture of a unified government policy aimed at downplaying the impact of COVID-19. We do not believe that this is in fact the case. There are examples of policies at the central government level that are clearly aimed at reducing the impact of COVID-19. For instance, President Joko Widodo issued partial lockdown orders, encouraged social distancing as well as allocated budgetary resources to address the issue. Our focus is to highlight the contradictions within the narrative offered by the Indonesian Government and how they were interpreted by the Indonesian people.

Social media offers health experts the capability of conveying accurate and robust information about the hazards of COVID-19 quickly and to potentially large and dispersed audiences. At the same time, social media also provides a platform (and rewards) for countering expert knowledge and spreading misinformation and disinformation. The concept of disinformation is not limited to COVID-denying individuals acting alone, but is also used as a tool for propagating misleading narratives from institutions, including the government.

In the early stages of the COVID-19 pandemic in January and February 2020, neighbouring countries Singapore, Thailand and Malaysia openly reported their first cases. In contrast, Indonesia did not officially report any cases at all. This is unsurprising. From the onset of the pandemic, the government's public response to COVID-19 has tended to be one of denial and of playing down the dangers posed by the disease. In February 2020, the World Health Organisation (WHO) was concerned that Indonesia had not reported a single confirmed case in a nation of nearly 270 million people. Given the densities of Indonesia's cities, COVID-19 cases were likely already numerous – and rising.

Indonesia's early COVID-19 denial can be seen in the way the relevant government authorities said that they were testing people. In contrast to worldwide agreement about the dangers posed by COVID-19, on 11 February 2020, the Indonesian Minister for Health, Terawan Agus Putranto told media 'They (other countries or experts) may not believe the reality (that Indonesian is zero COVID-19). But it is the truth; why do they think it is not reality?' ('Mereka boleh heran tapi itu kan kenyataan. Kalau kenyataan itu mau dianggap mengada-ada gimana'.)

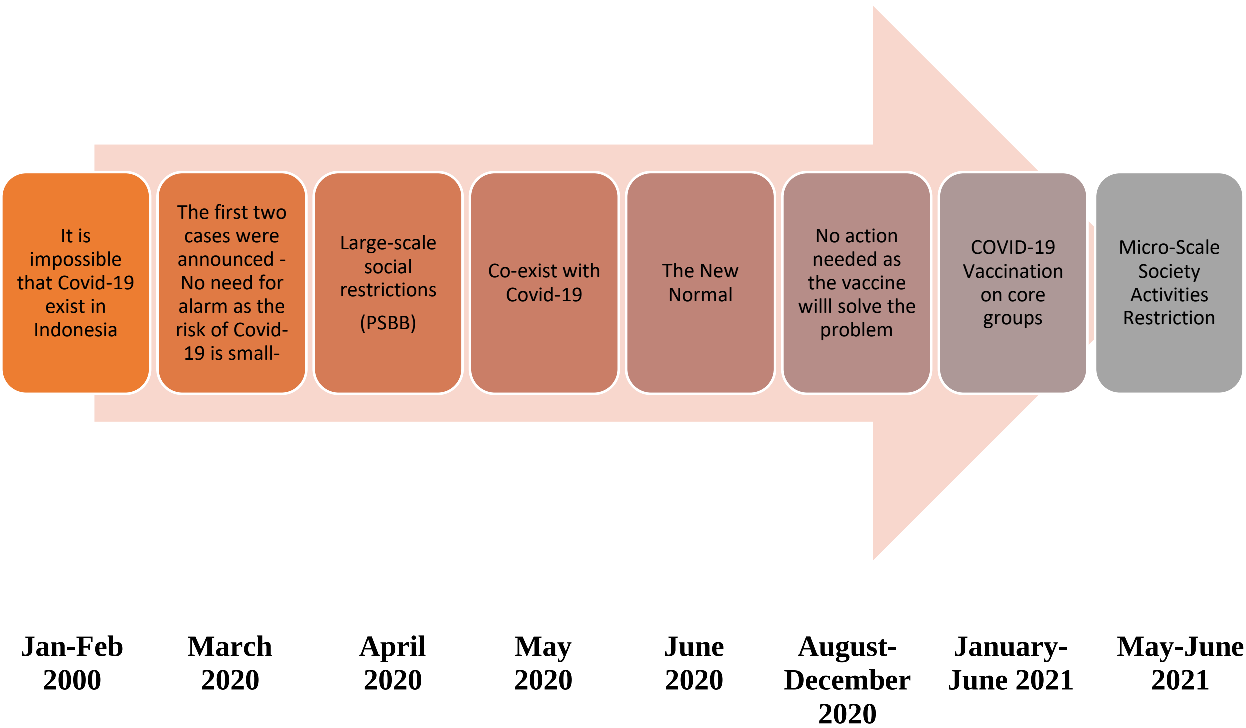

Figure 4. The COVID-19 Chronicle in Indonesia in 2020-2021
Source. Developed by Najmah

On 2 March 2020, the government officially announced the first cases of COVID-19. As the disease gained ground, shortages of personal protective equipment (PPE) for health workers became a worrying issue. Health workers reported having to wear raincoats as substitutes for PPE.

In January 2021, the new Minister of Health, Budi Gunadi Sadikin, acknowledged the mishandling of COVID-19 response strategies, stating that ‘we are now busy mopping the floor during rainy season, but we forgot to repair the damaged roof.’

Seeds of mistrust

Cognisant of the economic turmoil brought by the pandemic both globally and locally, by May 2020 the Indonesian government had backtracked from its original control measures. In April, Bank Indonesia had revised its projection for Indonesia's economic growth to fall by 50 per cent from the initial projection of 4.6 per cent to 2.3 per cent. Its COVID-19 strategy evolved into an official policy described as the ‘New Normal’. The ‘New Normal’ represented a reversal of large-scale social restrictions and was interpreted by many Indonesians as ‘back to normal’. We asked our respondents what they understood ‘new normal’ to mean:

Anti told us, ‘[With the] New Normal, we aim to return to normal activities, but still need to maintain our health’, and Eni explained, ‘New Normal is back to normal; the condition is getting better.’

A corollary of COVID-19 denial was the Indonesian government’s public information campaign, which was unclear. President Joko Widodo went on record saying that it was possible to have both strict health protocols in place and for people to go about their lives normally. In May 2020, he said ‘We must coexist with COVID-19’; the President’s advice seems to suggest that people can go back to living "normally" – but still must adhere to *abnormal* restrictions and protocols.

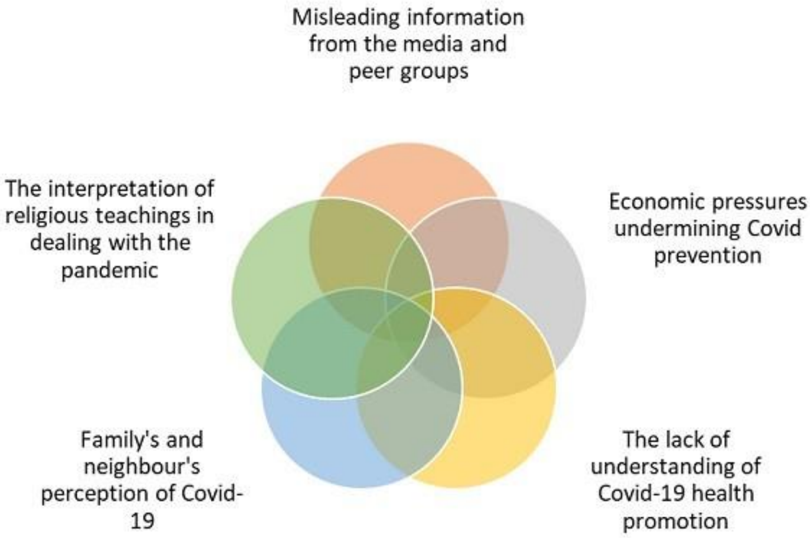

Figure 5: Some factors that may intersect with the New Normal perception of COVID-19 / Najmah et al.

This confused and confusing official messaging contributed to COVID-19 denial gaining traction. The COVID-19 denial narrative began to play a role in how health professions in Indonesia were perceived. Many Indonesians began to believe that health professionals were over-diagnosing COVID-19 cases at health centers. Rumours spread that health professionals were profiteering by falsely diagnosing patients and requiring unnecessary and pricey COVID-19 tests. Questions were also raised in the media as doctors were accused of extracting economic benefits by asking every patient to get a COVID-19 test at a rough cost upwards of Rp 150.000 (USD $10), regardless of the presence or absence of symptoms. Given this circulation of misinformation, people became afraid to visit public hospitals at all out of fear of expensive misdiagnoses or unnecessary tests.

Local contexts

Economic pressures clearly played a part in undermining COVID-19 prevention measures. Anti-COVID policies, including PSBB, forced many people into choosing between risking infection by leaving home to earn a living, or staying at home and enduring conditions of deprivation and slipping into poverty. This impossible choice disproportionately affected Indonesian women, many of whom earn a living from vulnerable jobs in the informal sector.

Policies aimed at supporting those affected by the economic downturn, such as incentives worth 2.4 million rupiah (USD$200) for micro-businesses, were tricky to put in place because many jobs are not officially recorded (through taxation systems or otherwise). The Government of Indonesia lacks sufficient data about who is and is not entitled to receive this financial aid. Consequently, the government's economic support has remained scattered, meaning that not everyone who needs it is receiving it, especially women.

The interpretation of religious teachings also plays a role in Indonesia's COVID-19 response. The Islamic idea of 'tawakal dengan Allah' (God willing), is a belief that what will happen in your life or the future is in God's hands. It follows, then, that people believe their lives are largely predestined to take a certain trajectory and that personal decisions may have little effect on the outcome of a person's life. As such, nothing can be gained from taking responsibility for making decisions in terms of responding to COVID-19. In effect, the idea is that taking action to minimise harm will have little consequence since god's will is all that matters – and COVID-19 and its consequences are part of that will. This understanding of religious doctrine challenged the government's efforts to integrate preventive measures effectively into people's daily lives. For instance, when we asked respondents why they did not wear a mask, they answered: 'Death is in God's hands; not due to Corona'.

Some religious leaders, however, provided effective guidance on keeping safe from COVID-19 by encouraging their followers to carry out early prevention. These leaders provided handwashing facilities and free masks in centres of Islamic gatherings, and it is interesting to note that the ritualistic ablutions before prayer in Islam synergise somewhat with COVID-19 guidelines.

Mixed messages

There are ranges of sometimes competing understandings about COVID-19 within Indonesia, both at the central government level and at the individual level. We have shown that without clear and unified messaging from the government and national health bodies, people receive a range of mixed messages about the impact of COVID-19 and what measures should be followed to slow infection. These competing narratives surrounding COVID-19 created an environment of uncertainty for people seeking reliable information about the disease, including preventing its spread.

A year and a half into the COVID-19 pandemic in Indonesia, we believe there is no sign that the Indonesian government is serious about handling this case. At the policy level, contradictions still abound; for instance, earlier this year, the government prohibited traditional Eid al-Fitr homecoming at the same time the Ministry of Tourism and the Creative Economy began reopening tourism destinations. Now, Indonesia is experiencing a shocking resurgence of COVID-19; its highest-ever case increase was registered on 17 June, and all signs point to lax travel restrictions, both international and domestic (including during Eid al-Fitr), as the culprit. The Ministry of Health has focused on vaccine delivery and seems to be ignoring prevention strategies, such as case tracking and enforcing health protocols (which are starting to slip, as evidenced by high-profile, large public gatherings, including those attended by President Joko Widodo).

The lack of a unified message is compounded by low digital literacy rates across socioeconomic classes. Health messages are even further diluted by the presence of multiple and often contradictory 'truths' proliferating on social media platforms. Even if people understand the true dangers posed by COVID-19, without adequate resources, they can only do so much to protect themselves if economic necessity drives them out into the workplace to earn an income and survive.

Chapter 3. Fears of pregnant women to seek antenatal care during the pandemic: Disrupted routine maternity in South Sumatra, Indonesia [7]

This talk explores the experiences of Indonesian pregnant women who experienced childbirth during the COVID-19 pandemic. Feminist-Participatory Action Research (FPAR) is as an important methodology to create a safe collective space for these women. Thematic analysis was undertaken to analyse data collected from 20 pregnant women in Palembang, South Sumatra. The data was collected during face-to-face and virtual interviews and focus group discussions as well as producing audio-visual materials. This talks provides an account of how pregnant women accessed maternal care during the COVID-19 pandemic. Three themes emerged including: 1) fear of accessing the COVID-19 test because they could get infected with COVID-19; 2) a difficult birth; 3) disrespectful antenatal care. We argue that this disrupted contributed to anxiety and fear among pregnant women as well as creating mothers' resilience in obtaining health services in Indonesia.

This section was submitted to Asian Studies Association of Australia (ASAA) Conference 2022

For mothers who know their pregnancy during pandemic, it is a great happiness for parents. Pregnancy is a part of motherhood roles as well as ‘ibadah’ or worship, therefore the participants enjoys their pregnancy during pandemic. Some common answers of participants about their pregnancy during pandemic: 1) “It is a blessing during lock down”; 2) “Pregnancy during pandemic is decision both husband and wives”; 3) “We waited for our first baby”. Fifteen out of 40 women in this study were pregnant during the pandemic. Eight out of 15 knew their pregnancy before the pandemic, between November 2020 to February 2021 and seven of them got pregnant during pandemic.

However, most participants expressed that ‘worry too much’ to get pregnant during pandemic, particulalry during accessing antenatal care to check their babies in

[7] This chapter will be submitted to Sexual and Reproductive Health Matters (under revision)

the womb. Other were worried to access COVID-19 test, worry to get infected with COVID-19 during pregnancy, and worry to acces hospital. Their worry disturbs mental health of pregnant women.

This section discusses experiences of accessing antenatal care during pandemic: 1) restriction in Antenatal care clinic to closing midwifery services; 2) a painful birth (a difficult labour) during pandemic; 3) no companion before and during caesarian surgery; 4) multiple miss-opportunities to diagnose HIV among pregnant women and their babies.

Respondent's characteristics: Pregnant women

Based on working status, 11 of them were identified themselves as a housewife or ibu rumah tangga and four of them were employee in public or private sectors, such as a nurse, a lecturer, and an administrative staff. The education degree range from Junior high school to master degree. On average, the income of family is between Rp 1.500.000 to RP 4.000.000 monthly.

Out of 15, only five women were accessed to COVID-19 test as they delivered their babies in a hospital. Other participants who delivered in a private midwifery practice or obstetrician clinic generally were not offered to COVID-19 test. Among non-HIV group, only For three out of 10 women who were tested with HIV test when they accessed antenatal care in puskesmas or hospital.

Table 1. Pregnant women characteristics in this study during pandemic

Name	Age	Public insurance	Antenatal care services	Place of delivery	Access to		Group	Note
					HIV test	COVID-19 test		
1. Veli	25	Yes	Puskesmas	Hospital	Yes	Not yet	HIV	A housewife, Senior high school
2.Widya	34	Yes	Private midwifery practice	Hospital	Yes	Yes	HIV	Family planning promoter Bachelor degree
3.Yuni	25	Yes	Puskesmas	Hospital	Yes	No	HIV	A housewife, a senior high school
4.Nurlaila	36	Yes	Private obstetrician clinic and midwife	Hospital	Yes	No	HIV	A housewife, Senior high school
5.Devi	23	Yes	Midwife and puskesmas	Hospital	No	Yes	Non-HIV	A housewife, vocational school (SMK)
6.Jihan	23	No	Private obstetrician	Private obsetrici an clinic	No	No	Non-HIV	A housewife, junir high school
7.Mardhiya h	24	No	Private obstetrician	Private obsetrici an clinic	No	No	Non-HIV	A housewife, a vocational school
8.Rini	23	Yes	Midwifery practice and puskesmas	Midwifer y practice	Yes	No	Non-HIV	A housewife, senior high school
9.Fitri	23	Yes	Private midwifery practice	Hospital	Yes	Yes	Non-HIV	An online seller
10.Ajeng	19	No	Private midwifery practice	Midwifer y practice	No	No	Non-HIV	A housewife, Junir high school
11.Dessy	28	Yes	Obstetrician clinic and Private midwifery practice	Clinic	No	No	Non-HIV	A employee, Bachelor degree
12.Windi	28	Yes	Obestetrician clinic	Hospital	No	Yes	Non-HIV	A lecturer, master degree
13.Rima	36	Yes	Private clinic	Private clinic	No	No	Non-HIV	A employee, Bachelor degree
15.Wenni	38	Yes	Hospital	Hospital	Yes	Yes	Non-HIV	A nurse, diploma

Mental Health Challenges for Pregnant Women During COVID-19

For many mothers in this study, their pregnancy, even during the COVID-19 pandemic, brought about great happiness. Pregnancy is a key part of the socially and state-sanctioned motherhood role in Indonesia. The motherhood role intersects with Islam, as it is considered a form worship or '*ibadah*'. Accordingly, pregnant women may enjoy higher status or social reinforcement during their pregnancy. A common response by participants about their pregnancy during the pandemic was: "it is a blessing during lockdown." However, most participants also expressed that they "worry too much about getting pregnant during the pandemic." Their concerns centered around being offered the COVID-19 test, getting infected with COVID-19, and accessing public health centers (*puskesmas*) and hospitals. Because of these concerns, most mothers in the study expressed that it was difficult to check on the health of their babies during the first year of the pandemic, as the first cases of COVID-19 were announced in Indonesia.

In addition to their interviews, Yaya (24 years), and Rini (23 years),[8] both from low income families, decided to make a puppet show and keep diary notes, to elaborate on their experiences. Yaya and Rini delivered their babies in August 2021, and October 2020 respectively. They both had to manage their pregnancies within the context of their midwifery practice shutting down; restricted visits to other public health services, as well as restricted partner access during consultations and delivery.

In March of 2020, on the way to the midwife, Mrs Yaya, who was pregnant for a second time, expressed her experiences of these difficulties:

> Mrs. Yaya: hmm, the midwife is closed. It's written that they are not accepting patients during the COVID-19 pandemic.
>
> Husband : so we want to back home or go to another midwife?
>
> Mrs. Yaya : let's go to the doctor.
>
> Husband : alright, let's go there.

[8] The are psuedonyms for privacy reasons.

Mrs. Yaya: After the clinic I went to was closed, it did not accept patients. I chose to go to another clinic.

Husband : Sir, [is] the doctor still accepting the patient? We want to do a pregnancy check.

Security : Yes, he does... But only the patient is allowed to enter the clinic.

Husband : Why, sir?

Security : That's the rule, sir. I am just doing my work.

Husband : All right, sir. Thank you.

Mrs. Yaya: Could we visit the obstetrician? Do they not accept or forbid us to bring our child?

Husband : No, you're the [only] one who can enter the clinic. Our child and I [can't] accompanying you.

Mrs. Yaya: Oh, all right, let's go home. I don't want to check my pregnancy, then.

Husband : Or we want to go to another midwife?

Mrs. Yaya: No, I don't want to. The ultrasound image is not clear. Let's go home.

Rini, 23 years old, who was in first pregnancy, shared a different story. In January of 2020, she went to the public health center (*puskesmas*) for a checkup. Everything was normal, and she was able to access a complete blood test, including an HIV test, and health workers provided supportive ante-natal care.

During this time however, Covid denial in Indonesia was still common, and many people, including health workers, were not aware of the existence or seriousness of the disease due to limited COVID-19 testing. Consequently Rini said there were no strict precautions in *puskemas* at the time. By March of 2021, the situation had clearly changed when she accessed *puskesmas. S*he was required to wash her hands, carry out social distancing between patients, and wait in the outdoor area of the *puskesmas*. When she arrived at the *puskesmas* and had just got off a trishaw (*becak*) with her mother, a health worker asked her to do a COVID-19 test as part of the early screening of visitors in the *puskesmas*:

Nurse: do you want [a covid] check, mom?

Rini: I want to check my pregnancy.

Nurse: Do you have any [covid] symptoms?

Rini: I feel nausea.

Nurse: [Regarding her pregnancy.] We cannot check you. [I]f you felt getting worse, such as having bleeding, then you can come to the *puskesmas* again.

Rini: Then I['ll] directly go home, and felt disappointed afterwards. I decided to access a private midwifery practice 'till my delivery (Rini's diary notes, 2021).

Another participant who was a working, pregnant mother during pandemic, faced similar problems, and spoke of the stress caused by COVID-19. In her case, she spoke of how the existance of the disease itself placed her considerable pressure during her pregnancy. When she thought of potentially catching the disease, it was unknown what effect it would have on her pregnancy and what impact it would have on the baby's health.

A further stresser caused by COVID-19, was how the burden of working at home added an extra burden to her pregnancy, particularly around meal preparation and nutrition (see Winda's poem in Expectations of women in Sumatra). These stresses were compounded when a close family member was tested positive with a COVID-19. Other participants were in a similar position.

Winda, 28 years old, a lecturer in a public university shared her experience during her second pregnancy, and working from home (WFH) during the first year of pandemic. Winda knew her second pregnancy in March 2020. Winda also was placed under a great deal of stress when she discovered her mother and grandmother, who lived with her, were diagnosed as COVID-19 positive. Her mother then suffered from severe symptoms and was hospitalised. The resulting hospitalization of her mother placed even greater stress on her, as she had to shoulder even more household chores and other responsibilities. Fortunately, Winda's COVID-19 test was negative. But being pregnant, exposure to COVID-19 raised many issues for her. She expressed her experiences through her diary notes:

The peak of concern finally arose when my mother, who lived in the same house with me, was confirmed positive for COVID-19 based on a

> PCR swab even with severe symptoms, so that she had to be hospitalized, even though we had contact, even my grandmother was confirmed positive but without symptoms so she had to isolate independently at home. This is certainly a heavy psychological pressure for me, what if I have been infected without realizing it, what if my first child or husband is infected and I have to take care even though I am pregnant that's all I can think of. Until we were in the same house and then we also did a COVID-19 check and thank God all were negative but the thought still popped up, don't you think there will be something positive in the future? Moreover, my husband has started to go to work as usual and every time he comes home with a story that a friend from his office is positive for COVID-19 makes me sometimes think, should my husband be told to sleep in another room so that I am safe? (Winda, diary notes)

Ani, 40 years old, a midwife profession with two children, was diagnosed COVID-19 in suburb district in South Sumatra and had to delivered her baby in COVID-19 procedure in a public hospital in Palembang. At the same time, her husband was hospitalised in ICU and her children were treated at home with asymptomatic condition of COVID-19. Initially, her family members were afraid of taking care of her children as she needed to travel to Palembang for her Caesarian section. Ani, shared her story through online chatting:

> I am traumatised by COVID-19, my two children and my husband also contracted COVID-19. I was also infected with COVID-19 during my last term of pregnancy. No one wanted to take care of my children because I had to be referred to the Palembang to delivery my baby. Finally, my brother-in-law got up the courage to take care of my asymptomatic children. I was referred to a different hospital from my husband in Palembang. I gave birth to my third child when my husband was unconscious and struggling in the ICU. In the hospital, the nurse only came into my room when injecting the medicine and immediately left me alone in the isolation room. After I delivered my baby, I was separated to my baby directly to prevent COVID-19 transmission. Thanks God (Alhamdulillah), my husband and my family were still given a second chance to live and we have been declared negative for COVID-19. I am traumatised, I am traumatised. For now, I am still closing my midwifery practice in my house (Ani, online chatting through WhatsApp).

The experiences of the participants highlight the disproportionate level of difficulty placed on the role of pregnant women by government COVID-19 initiatives. These added burdens may be seen in how health workers, including midwives and obstetricians, a frontline for antenatal care, may choose to close their practices and not provide their services. When services were offered, they highlighted a disconnect between the government's COVID-19 requirements for social distancing and cultural practices within Islam. If health practices remained open and provided services, health workers limited only pregnant mothers to come into obstetrician's room or engage in the delivery process without family (husband or parents). The issue here is, within Malay and Islamic cultures, not all pregnant women are comfortable with a health professional checking their baby in utero without the attendance of their husband in a closed consultation room.

A further issue with social distancing, is health offering online consultation (telemedicine). Telemedicine may not be an effective method for pregnant women from low to middle income families who are used to meeting directly to consult their health concerns. Internet access remains an issue in Palembang, particularly during the COVID-19 economic downturn and its resulting effects on unemployment.

A further issue identified by the research participants was a fear of the COVID-19 test, as a requirement before the delivery. In our study, some participants spoke of the fear that the test was fraudulent, i.e. a revenue gathering exercise by health professionals, and therefore expected to be isolated as Covid patient. The result being that they chose not to deliver their babies in hospital, out of this fear, adding to an already challenging situation. For those who was confirmed to have COVID-19 or their family members were confirmed to have COVID-19, pregnant women need to deal with silence stigma surrounding COVID-19 at family and health services level, fears of transmitting COVID-19 to their babies and to be resilient to overcome their mental health condition. Experiences such as these, highlight how the issues identified in Section 2, have an impact at the individual level. We now turn to the experiences of HIV positive women interviewed in our research, and how COVID-19 exacerbated HIV treatment in Indonesia.

Missed Opportunities: Preventing HIV Transmission from Mothers to Babies.

In this section, we explore how COVID-19 based policies negatively intersect with the silence surrounding HIV treatment in Indonesia. To elaborate on this theme, we share the three stories of HIV positive Nur, WidiWida and Nora,[9] who were all pregnant at the time of the research.

[9] The names of the participants have been changed for privacy reasons.

Nora, 35 years old and *Ibu rumah tangga*, was shocked to discover she was HIV positive when she and her first child were diagnosed with HIV in November 2020. Nora then found out her HIV status when her second pregnancy reached 8 months. While many people avoided visiting hospitals during the pandemic, Nora did not have a choice, because of herself and her child's HIV status, needed medical supervision on a weekly basis. Nora also needed to access Antiretroveiral therapy and undertake Caesarean section in Prevention of mother to child of HIV transmission (PMTCT) services in the hospital to prevent HIV transmission to her second child.

These visits became an issue when some of her online contacts and family members began pressuring her to abstain from these visits by asking her "why do you need to go to hospital during [the] pandemic? Won't you be afraid of seeking health services in hospitals!" as well as other questions. Nora still lived in her mother-in-law house, therefore Nora and her husband disclosed their HIV status to her husband's family to stop these frequent questions to her. However, Nora's husband did not allow Nora to disclose their HIV status to Nora's family.

She responded that she was not afraid of COVID-19, as she needed to focus on her child's health, arguing "HIV is more dangerous than COVID-19," as the virus remains present in her body. While not wishing to condemn her difficult choice as an HIV positive mother who needed medical services for herself and her children, we cannot help but infer that her decision to sustain regular hospital visits, may have been influenced by mixed governmental messages downplaying the deadly nature of COVID-19, especially in the case of an immune-compromised patient. Furthermore, HIV positive Indonesians suffer an added, and potentially life threatening difficulty, with a culture of HIV denial prevalent within Indonesian government policy, at the individual and wider social level, but also within the professional medical sphere. This uncomfortable silence may be seen in how Nora was treated by both her family and the health professionals she so desperately needed.

Nora is an example of the late diagnosis of HIV among *Ibu rumah tangga* (housewives), where health workers may still think "it was not possible that [she] could be infected with HIV" (Nora, Interview). The cultural silence may be seen with how Nora's parents thought that it was impossible for a good and religious man to get infected with HIV from his sexual behaviour outside of the marriage setting (Field notes, March 2021).

In 2020, Nur, (38-years-old) needed to treat her third malnourished daughter, Ana (18 months). She needed to stay for a week in a public hospital. She recalled that a doctor called Nur into the emergency room in a public hospital, and as it was a crowded room, she disclosed Nur's child's HIV status with a low tone of voice in the corner of the room. 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. Nur was aware of a doctor in a private hospital that was recommended.

> In the private hospital, my daughter had been treated for her malnourished condition. One nurse explained that the specialist, doctor Nando (all names are pseudonyms) specialised in her daughter's condition but had other work and could not treat my daughter. Therefore, the hospital decided to refer my daughter to the public hospital. After arriving in the emergency room in the public hospital (at 9.30 am), the doctor explained the HIV status of my daughter. I was shocked to learn that she was infected with HIV. I was just aware that the doctor, who was mentioned in the private hospital, is a doctor who is specialised in treating HIV-positive patients (Nur, Informal Interview).

The silence surrounding HIV in health settings means midwives and obstetrician often do not talk about HIV to their pregnant patients. Health workers did not recommend pregnant women do a complete blood test, including HIV in their closest public health centre or *puskesmas,* midwifery practices and obstetrician practices in clinics or hospital. Similar institutional barriers occur when nurses and doctors are reluctant to discuss and refer HIV positive patients to specialists. Our third interviewee Widi also had similar experiences.

Widi, an HIV positive working mother, had caesarian sections with her two previous babies. She lived in suburb area. In her case, she had already given birth as an HIV positive mother and was experienced enough to prevent her third child from becoming HIV positive through the use of caesarian sections. However, for her third pregnancy, during pandemic, she opted for a vaginal delivery for her baby. She said that every month her obstetrician checked her pregnancy, but she did not disclose her HIV status as she experienced discrimination when she asked for a referral letter for her therapy. At the same time, In January 2021, Widi decided not to disclose her HIV status and risk transmitting HIV to her child through a vaginal delivery in her local hospital. Widi expressed her reason for doing so was that she feared breaking COVID-19 travel restrictions by accessing preventing mother-to-child transmission (PMTCT) of HIV services in Palembang, a four hour journey by car from where she lived.

After the delivery, her husband asked Widi to breastfeed her baby in the hospital as he was afraid the staff and her mother in law would discover her HIV status. At home, she stopped breast feeding and replaced it with formula milk. Widi husband to her:

> I was initially hesitant to raise my child, because I was afraid that I might transmit HIV to my baby. There is an 80% chance that my child would be infected with HIV. However, my husband supports me to treat our baby together if our baby gets HIV. (Widi, Online Interview through WhatsApp)

The experiences of the above women, suggest that a parallel my be drawn between the cultural silence surrounding HIV and how it intersects with COVID-19 in Indonesia. Both diseases generate a culture of denial, sadly resulting in unnecessary or preventable death and suffering. Both diseases have disproportionate and gendered effects, particularly in the area of socially constructed roles as they pertain to women's roles the home and in the public sphere. Finally, both diseases require strong and consistent policies from central government to prevent further transmission of the diseases and change the culture surrounding them.

Conclusion

Similar to previous epidemics, COVID-19 has challenged Indonesia and exposed how the nation as a whole governs itself, putting a spotlight on the important role of strong scientific input within the policy creation and propagation process. This research has drawn the attention of the reader to the way Indonesia has constructed a dated governmental gender narrative, falsely painting women as a heteronormative subject within the private sphere. Documenting the experiences of the women who were part of this study has exposed how mixed messages of Covid denial and assumptions of heteronormative sexual practices can have destructive effects on Indonesian society, particularly those living in precarious economic conditions. It is hoped that this chapter contributes to a broader, more open discussion on the role of the state and how it both acts as a gatekeeper for impeding the progress of women in Indonesia as well as having the potential to be a champion of women's rights with the broader Islamic world.

Chapter 4. Endless stigma of HIV for women with HIV during COVID-19 Pandemic[10]

Figure 6: Endless stigma of HIV and COVID-19 in Inside Indonesia (May, 31st 2021)

I came to the hospital to give birth
And i said that I have B20 (medical term for HIV)
But I was considered as a badly behaved woman
As if I was going to infect them, even though I was a good mother
And I was afraid to infect HIV to my baby and health workers
I had an unpleasant stigma
As if I'm going to transmit HIV to others
Even though I disclose my HIV status in the health setting
But I didn't get a respectful antenatal service
I was even accused of being badly-behaved (unresponsible) mother and having multiple partners
Whereas in my heart, I don't want to pass this B20 on to other mothers
I am the head of the family and a breadwinner
Alhamdulillah, I really thank God
My three children are not infected and negative

A deep voice from an HIV-positive mother, Yana's letter, March 2021

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[10] This Yana and Nika's stories in this chapter has been published in Inside Indonesia, 31st April 2021. Retrieved in https://www.insideindonesia.org/endless-stigma-of-hiv-and-covid-19

1. Introduction

HIV-related stigma is still rampant in Indonesia. Stigma is "an illuminating excursion into the situation of persons who are unable to conform to standards that society calls normal" (Goffman, 1968)[11]. According to HIV-positive mothers in this study stigma means bullying-"*ngatoi*", insulting -"*menghina*", isolating-"*mengucilkan*", fearing-"*takut*", dan terrible-"*mengerikan*" (see Figure...).

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 (Parker & Aggleton, 2003)[12]. We define HIV-related stigma as negative beliefs, feelings and attitudes towards people living with HIV and their families; for people who work with HIV service providers; for members of high-risk groups (IDUs, female sex workers, men having sex with men); and for married women living with HIV.

Figure 7: HIV and COVID-19 related stigma intersecting for mothers living with HIV from themselves, family, neighbour, society, health workers and friends.

[11] Goffman, E. (1968). Stigma: Notes on the management of spoiled identity: Simon and Schuster.

[12] Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Social science & medicine, 57(1), 13-24.

During the first year of the COVID-19 pandemic in Indonesia, we found stigma attached to HIV extended to personal and community judgment to COVID-19 for women living with HIV who sought health services during delivery or therapy for other diseases. Our study found the women lose either way. If they don't disclose that they have HIV they can't get treated properly but if they do disclose they still can get treated because medical professionals refuse to treatment for fear of HIV. Below we share some of the stories we heard.

2. Common perception of mothers and wives with HIV

Within inequality gender in a strong patriarchal culture, twenty pregnant women who are free of HIV and twenty mothers living with HIV, describe common perception of HIV-positive women in the general population. Some perception about HIV and women are generally 'negative', including : 1. Women with *Penyakit kotor* (dirty diseases); 2. Disease for women with *gonta ganti pasangan* before marriage or unfaithful wife (wanita tidak setia)*;* 3. *Perempuan hina* (Despised women); 4. *Ibu rumah tangga* is impossible to get HIV, except *Perempuan tidak benar* (not good woman) and *wanita nakal* (bad behaviour women) (see Figrue 1, 2, and 3). Sadly this stigma attached on HIV was not only spread among community but also was normalised in health settings (Najmah, 2019).

> Yes, society and health workers will think negative to HIV-positive women. People living with HIV relate to people who like buy sex or access to female sex worker, therefore they more likely to suffer from Sexually Transmitted Diseases. We know there are other risk factors to get infected with HIV, such as a good woman may access to beauty therapy with non-sterile sharp equipment, however, negative-stigma was always at the first though, before women with HIV explain about her experience[13].

[13] Yo masyarakat dan tenaga kesehatan pasti jingoknyo tu negatif dulu yo namonyo keno HIV tu pasti tanggepan wongnyo yang galak bejualan atau bejajan nah cak itu nah. Namonyo keno penyakit kelamin tu itulah pasti. Padahal kan banyak faktor lain gitu, seperti gambanyo dio ni perempuan baik-baik, caknyo dio ni dapatnyo dari salon kecantikan. Jadi dio nak mempercantik diri tapi alat-alatnyo dak bersih. Tapi pasti negatif tulah, stigma negatif tu pasti itu dulu, sebelum akhirnyo yang bersangkutan tu menjelaske di mano dio dapatnyo

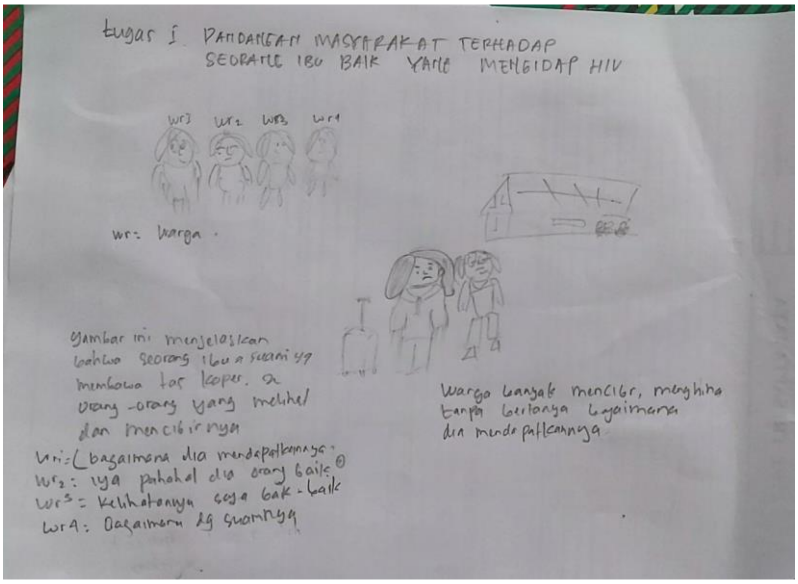

Figure 8: Perception of a good mothers and wives living with HIV (Najmah documentation, drawing by Rima, mother with three kids, non HIV)

Illustration: her husband accompanied her wife to access antiretroviral therapy in hospital, while many people 'mencibir (...) and 'menghina' without asking how she could get infected with HIV.

Person 1 :How she could get infected with HIV?
Person 2 :I think she is a good mother
Person 3 :She may look like a good mother, the reality may be not
Person 4 : How about her husband?

This institutionalised stigma was expressed by HIV-positive mothers as unfair attitude for them who were a good mother, mother with a good manner (*perempuan berakhlak baik*) as well as a breadwinner, but still have a risk to get infected with HIV. Sadly, the women who disclose their HIV status to their family may be discriminated by their family, including their children or husband who are free of HIV.

> I am a housewife with HIV, a widow; I was stigmatized by my family. My children felt the same though they are free of HIV. Stigma was not hurtful not only for me, but also for my children. Stigma was very painful for my children. We were excommunicated, mocked, insulted; it hurts a lot (Karmila, an HIV-positive mother and widow with three children)[14]

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[14] Saya adalah seorang ibu rumah tangga yang terkena penyakit B20. Saya diberi stigma oleh keluarga, dan anak-anak saya pun terkena stigma mereka. Walaupun mereka tidak terinfeksi B20 namun mereka terimbas stigma B20 ini. Sangat menyakitkan untuk anak-anakku. Aku dikucilkan, dikata, dihina itu sangat menyakitkan".

Stigma on HIV still overweigh than COVID-19

Stigma on COVID-19 was overwhelming in the early of pandemic, however stigma related to HIV was still never endless. The mode of HIV transmission might be contribute to moral judgment and negative perception on people living with HIV. HIV was relate to genital, reproductive system, and sexual activity, while COVID-19 was transmitted through air, not sexual activity.

> Stigma on HIV is always negative as mode of HIV transmission relate to reproduction and the genital area, so the stigma is negative. COVID-19 has different mode of transmission, the virus spread through air, not from fluids or sexual activity (online FGD with group of working mom) [15]

Though stigma on COVID-19 is not morally judgment like stigma on HIV, the study highlights women living with HIV suffer from double burden of stigma during their access to health settings during this pandemic. For instance, in the following study cases, Nika was directly treated in an isolation room for COVID-19 due to her severe cough, and Yuni was prayed to be COVID-19 after she always complain on unfair treatment for her and her baby during her delivery.

3. Respondent's characteristics: HIV-positive women

Out of twenty women living with HIV, most of them disclose their HIV status to their family, including their parents and siblings. However, only four out of 20 the women disclose their HIV status to health workers, such as private practice or public health centre (*puskesmas*). Most of them were brave enough to open their HIV status in health services related to HIV, such as taking Antiretroviral medicine in HIV services or giving birth their baby in PMTCT services.

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[15] Kalau HIV kan stigmanyo negatif tulah, karena dio berhubungan dengan reproduksi, daerah kelamin, jadi stigmanyo negatif. Kalau covid ini kan idak, wong keno virus keno ke kito karno udara, bukan melalui cairan atau seksual.

Table 2. Respondent's characteristics: HIV-positive women

Name	Age	Marital status & Owning house	Origins	Disclosure of HIV status			Experience of stigma and Discrimination		
				Family	Neighbour	Health Workers (not in HIV services)	Family	Neighbo ur	Health workers (not in HIV services)
1. Veli	25	Married Contracted house	Palembang	Sister and husband	X	X	X	-	V
2.Widya	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.Nurlaila	36	Married Parent's house	Palembang	Husband and husband's family	V	X	X	-	X
5.Ika	36	Widow Owning house	Palembang	Mother, sister and brothers	X	X	X	-	V
6.Endang	49	Widow Parent's house	Palembang	Family	X	V	X	-	X
7. Karmila	41	Widow Parent's house	Palembang	Parents and siblings	X	X	V	-	X
8.Daviyah	40	Second married Owning house	Palembang	Husband's fmaily	X	X	X	-	X
9. Octa	44	Widow Parent's house	Palembang	Family	X	V	X	-	V
10.Lium	33	Divorce Parent's house	Palembang	Family	V	V	X	V	V
11. Tika	33	Married Owning house	Lahat	Family	X	X	X	-	V
12.Rini	40	Widow Owning house	Palembang	Nuclear family	X	X	X	-	-
13. Mawar	44	Widow Owning house	Medan	Nuclear family	X	X	X	-	X
14.Xani	35	Married	Palembang	Family	X	X	X	-	V

		Owning house							
15.Mona	33	Second married Contracted house	Palembang	Nuclear family	X	X	V	-	X
16.Putri	38	Married Owning house	Palembang	Husband	X	X	X	-	V
17. Maya	36	Second married Contracted house	Palembang	Parent and husband	X	X	X	-	X
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	-	X
20. Mulan	31	Second married Contracted house	Palembang	Second husband	X	X	X	-	X

4. Yana's story: "It is better to treat COVID-19 patients than an HIV-positive patient"[16]

In October 2020, Yana (25 years old) was rushed to hospital to deliver her fourth baby. Based on her previous experiences, she knew she needed to access Prevention of Mother-to-Child of HIV transmission (PMTCT) services at one public hospital in Palembang. Yana was aware she needed to disclose her HIV status in order to protect health workers from HIV transmission and also to access prophylaxis therapy for her baby after her delivery.

Yana was treated in the Emergency room and was asked questions related to COVID-19 symptoms for screening purposes. The health workers treated her well until she disclosed her HIV status. After she disclosed her HIV status, the nurse pushed her body and told "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"[17]. Another health worker said to her:

> 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 pray me for that. If I get infected with COVID-19, you would be sick too.[18] Then the health worker was silent.

Then, Yana exercised her rights and replied:

> I have right, I can make a report for your unfair treatment, please don't treat me badly. For my HIV status, it is not my own willingness, I also did not want to be infected HIV too. My operation schedule failed as the date of prediction was on 15th December 2020. The health workers keep talking though I was in bleeding and in pain. My heart was broken. Help me, God (Yana). [19]

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16 Lebih nginiin pasien covid daripada nginiiin pasien b20

17 Katanya, daripada aku giniin pasien B20, mendingan aku giniin pasien corona katonyo cak itu

18 "Nah kamu kalo tes, kamu bakalan positif katanya. Enggaklah bu kataku. Kalo aku emang, aku selama ini sehat-sehat aja aku bilang kayak itu. Eh jangan didoain juga lah bu kataku. Kalo aku kena corona ibu lebih ini. lalu langsung diem dia.

19 (Terus aku jawab, aku punya hak dong, aku jawab, aku bisa ngaduin kalian loch kataku, janganlah kayak gini ku gituin. Memang bukannya kehendak aku. Yang kemaren operasi gagal kataku. Prediksi ini bukan tanggal ini kubilang gitu kan. Seharusnya tanggal 15 kata dokternya pub kayak gitu ku bilang. Pokoknya bu ocehan bu. Pas darah itu aja aku masih pendarahan. Uuh sakit ati aku didalam dicaci inilah kataku. Ya Allah (Yana)

After her complaint, another doctor helped Yana. Yana expressed the importance for the HIV-positive mother to exercise her sexual and reproductive rights in order to access respectful treatment and get the support of health workers for HIV-positive women, particularly during her delivery. She highlighted that HIV-related stigma never vanishes, therefore HIV-positive women and their husbands need to be a resilient for the sake of their child's health. She felt better after her uterus (womb) was cleaned properly and said heap gratitude to the second doctor.

> Then another doctor helps me, and said to one midwife who treated her "if you cannot finish your work to help this mother, it is better not to help her delivery". The unprofessional treatment for HIV-positive pregnant women would kill the mother and baby, the doctor added (Yana)20.

Yana and her husband are among the rare groups living with HIV in Indonesia who dare to speak up and argue with health workers. It is an unfortunate reality that 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. Of course, the number of those who can do this remains very small, as most people choose to remain silent because they are powerless.

5. Nika's story: Disclosure or not disclosure HIV status during COVID-19 Pandemic

In July 2020, 33-years old Nika suffered from appendicitis and needed to undergo surgery. She decided not to disclose her HIV status so that she would get respectful health treatment. Nika believes that the HIV-related stigma has become worse during the pandemic. Based on her experience, every patient was suspected of having COVID-19 in the first year of the pandemic, and disclosure of HIV status meant a double burden of stigma for HIV-positive women in health settings. She recounts that:

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[20] *(Jadi dimarahin lah dokter yang nanganin aku yang pertama itu sama bidan yang lain itu kan. Katanya ibarat kalo kamu kerja ga nyelesain itu, ga usah dipegang lah mending. Ini kayak gini, sama aja kamu kayak membunuh orang katanya)*

> [In July 2020] Yes, I seek health services in a hospital, I do not disclose my HIV status. There is the strong stigma of being an HIV-positive mother, I cannot imagine if I disclose my HIV status. I really do not want to open my HIV status. You know why? I access the third class facilities (there are 5-8 patients in a room), stigma is strong during the COVID-19 pandemic (every patient was suspected to COVID-19). I am alone during my hospitalisation, no companion (from family) was allowed. If I open my HIV status, people will not treat me (run from me), no one will take care of me, inject the medicine for me. In my observation, health workers are still afraid of HIV compared to COVID-19.[21]

In February 2021, Nika was sick again and she went in a rush to the emergency hospital with her mother. She was coughing and had difficulty in breathing. She was directly diagnosed as COVID-19 and was treated in an isolation room for 10 days although a few days her result showed negative for COVID-19. Nika expressed:

> I needed to wait for three hours to get treatment in the emergency room. Due to my symptoms related to COVID-19, frequent coughing and difficult to breathe, I was treated in an isolation room directly. Well, I got the benefit I did not need to share with another patient who may be positive-COVID-19. A robot, the name is Raisa, also helps to provide medicines for me, nurses will visit us only at a certain time (Nika).

6. Lesson to learn

HIV-positive women are aware that every woman may deal with different stages of stigma from family, health workers, friends and neighbours (click here for a link to a video we made[22]). Therefore, they need to consider to whom they need to disclose their HIV status. For note, normalization of institutional stigma and discrimination was rampant in health setting for women living with HIV[23]. During the pandemic, HIV-positive women need to brave enough to seek health services while most people may

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[21] *Iyo di Palembang nilah, rumah sakit, idak idak buk idak bukak status be stigmanyo kuat, cakmano buka status nambah. Aku dak galak nian buk buka status. Sebab apo buk idak bukak status be stigmanyo la kuat, kito kan pake kelas tigo buk. Enaknyo buk idak katek (tidak ada) yang nunggu aku, iyo aku dewek. Stigmanyo kuat nian, apo lagi amen buka staus. Ai belari galo, dak katek yang na ngurusin infus kito, na nyuntik kito. Malah yang ketakutan dio (tenaga kesehatan) masih tulah dengan HIV. HIV itu lebih ditakutken daripada Covid-19 (Nika)*

22 The intersected HIV and Covid-19 related stigma for mothers living with HIV. Link video: https://www.youtube.com/watch?v=MvuVKfgRvhw

23 *Najmah, Andajani, Sari, Davies S.G. 2020. Perceptions of and barriers to HIV in Indonesia. https://www.tandfonline.com/doi/full/10.1080/26410397.2020.1848003*

avoid to access the hospitals. The prospect of every patient being diagnosed with COVID-19 was rampant in the community in the first ten months of the pandemic.[24]. We argue that the women may lose either way, through disclosing or not to disclosing their HIV status in a health setting. Therefore, HIV-positive women need to be resilient, drawing on support from their family, supportive health workers to access health services for the sake of their children's and their own health.

The government needs to create the supportive health systems, including peer education for health workers who are able to provide safety and confidentiality for HIV-positive women. Therefore, the women feel safe, feel protected and appreciated as a good and religious mothers and wives to reduce the institutionalized stigma in society. In this context, we suggest Ministry of Health in collaborated with Ministry of Education need to include sexual and reproductive health rights and gender equality, particularly for HIV-positive women in the health curriculum.

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24 *Najmah et al. 2021. 'Believe it or not, it's Covid-19': Family perceptions of Covid-19 in Palembang, Indonesia. Retrieved from http://intersections.anu.edu.au/issue45/najmah2.html*

Chapter 5. What's behind COVID-19 vaccine hesistancy in Indonesia?[25]

Figure 9: What is behind vaccine hesitancy in Indonesia in NEW MANDALA

As Indonesia pushes forward with its COVID-19 vaccine rollout, the nation faces substantial obstacles. Trying to administer vaccines to an archipelagic population of 260 million people spread over 6000 islands is no small task. But logistics and resources aside, Indonesia is facing a further hurdle: vaccine hesitancy.

In August 2020 polls suggested that 27 percent of Indonesians were hesitant to receive the vaccine and by December the results of a phone survey suggested only 37% were sure they would accept vaccination when it was offered.

What is behind this vaccine hesitancy? To uncover the reasons, we conducted on-the-ground research in South Sumatra, interviewing 50 women in the first few months of 2021 who had key vulnerabilities: 20 of these women were living with HIV; 20 were pregnant during the last 12 months; and 10 were front line health workers.

Our interviews revealed four key factors behind vaccine hesitancy: concern that the vaccine is not halal (permissible in Islam); fears over Sinovac as it comes from

[25] Published in New Mandala, 25 May 2021 in collaboration with Kusnan and Sharyn Graham Davise. https://www.newmandala.org/whats-behind-covid-19-vaccine-hesitancy-in-indonesia/

China (and has imagined links with Communist contagion); vaccine coercion; and belief in alternative ways of safely and effectively guarding against COVID-19 such as good hygiene practices.

1. The vaccine is not halal

> I do not want to be vaccinated because the vaccine is from China, and there are pig parts in the ingredients. It is haram (forbidden) to put pig parts into my body. We will go to hell if we do it. (Yaya, a 50-year-old housewife) (all names are pseudonyms)

Indonesia has a relatively high acceptance rate of regular immunisation regimes. Indeed, around 80 to 90 percent of all babies under the age of one receive immunisations. Mothers we talked to noted that prior to COVID they would travel some distance and stand in long lines at public health centres to ensure their babies were fully immunised. This account suggests that Indonesia is a vaccine-accepting country. Furthermore, the current MMR (measles, mumps, and rubella) vaccine is made in India and is widely suspected to contain pig products. Yet there has been no large-scale refusal of this vaccine in Indonesia, despite it not being certified halal.

But there is heated debate in Indonesia currently around the Sinovac vaccination, which is the main vaccine administered in Indonesia at the moment for COVID-19. Sinovac was developed by Chinese biopharmaceutical company Sinovac and is now made in partnership with Indonesian state-owned pharmaceutical firm PT Bio Farma. While AstraZeneca, Novavax and Pfizer have publicly stated that there are no pork products in their vaccines, Sinovac has refused to reveal whether its vaccine contains any pork products.

Given Indonesia is home to the largest population of Muslims in the world, not being able to confirm the halal status of the vaccine worries many. This worry persists despite Vice President Ma'ruf Amin, an influential Muslim leader, declaring that in emergencies such as a global pandemic, the vaccine does not need to be certified as halal to be permissible. But fear continues, and it continues despite other widely accepted vaccines (e.g. MMR) not being declared halal. We suggest, therefore, that it is not halal status on its own that is provoking vaccine hesitancy. Hesitancy is also due to the fact that there is suspicion of China.

2. Fear of Sinovac and China (and imagined links with Communism)

> As far as I know, China bought vaccines from Europe, and Indonesia bought vaccines from China. Think about it! (Nay, 33-year-old working mother)

Part of the reason for vaccine hesitancy is that people are not convinced that the Sinovac vaccine is effective. As Nay suggests above, consumers are suspicious of why China would import a vaccine from Europe if their domestically produced one was effective.

But hesitancy also comes from a general distrust of China, including health products made by Chinese companies. This distrust extends from Indonesia's long standing tension with Communism, which continues to be banned in Indonesia. Rumours thus circulate that China might be waging a proxy war against Indonesia by delivering a vaccine that might have fatal consequences.

Further, women told us they felt China was pushing a vaccine (of dubious efficacy and with potentially deleterious side effects) just to make money. This again taps into harmful stereotypes in Indonesia that Chinese businesses want to make a profit at any cost. Added to this profit discourse is the widespread belief that people from mainland China are coming to Indonesia to take away local jobs. There is thus a kind of grass-roots collective resistance against China and Chinese products, including vaccines, as Nika, a 29-year-old mother summarises:

> The efficacy of the vaccines has not been proven with evidence. It could turn out to be medical malpractice. We hesitate then to take the vaccine and wonder if it is a vaccine or if it's just vitamins. And where did the virus come from? And where is the vaccine made? Both in China! So maybe COVID-19 vaccines are just made for economic reasons to benefit China. China, you know, they are Communists. We have become experimental subjects, yes, guinea pigs (*kelinci percobaan*, literally test rabbits). For me, it is better to maintain our health, trust our body, and if we can maintain our health, then what is the COVID-19 vaccine for?

Vaccine hesitancy also stems from public distrust of the Indonesian government, which many people see as being too close with China. For instance, women noted that the government has not raised the issue of Sinovac needing to pass clinical trials and have its efficacy proven. Women mentioned that the Sinovac vaccine had not (according to their understanding) passed the Stage III Clinical Trial and they noted that the government had not transparently explained this. Women thus worried that the vaccine was not safe because it was only approved through an emergency permit granted by Indonesia's Drug and Beverage Regulatory Agency. There is thus palpable suspicion of the vaccine in Indonesia and when this suspicion is met with a coercive vaccination program, you have a recipe for vaccine hesitancy.

3. Vaccine coercion

From early January 2021, there was rampant social media messaging saying "I am ready to be vaccinated." Such posts were shared by community health centres, hospitals and public health departments, healthcare organisations, and health workers themselves. There was hope that people would get vaccinated in good faith.

But shortly thereafter the government imposed the threat of fines of up to Rp 5 million (AUD$450) for people who refused the vaccine or who spread anti-vaccine messages. These fines were particularly aimed as health care workers and teachers, who were first in line for mandatory COVID-19 vaccines. Presidential Decree Number 14 of 2021, verse 13A, point 4, states:

> Anyone designated as a core target for the vaccine, and who refuses the vaccine, will face an administrative sanction, including postponing or stopping social aid, postponing, or stopping administrative government services; and/or a fine.

The coercive nature of the vaccine rollout has put many Indonesians offside, as Ati, a 30-year-old nutritionist, revealed: "We cannot reject the vaccination for COVID-19. Thirty of my friends refused the vaccine on health grounds and they were interviewed by staff from the Ministry of Health and the Public Health Office. After the interview, 28 were compelled to be vaccinated; only two had their wishes not to be vaccinated upheld."

The coercion to be vaccinated has concrete implications, as Hana, a 35-year-old woman who works in a public hospital noted:

> From the bottom of my heart, I did not want to get the COVID-19 vaccine. However, we would lose our job if we did not get the COVID-19 vaccination.

Lala, a 30-year-old nurse, also mentioned that as a health worker she was obliged to get vaccinated and that her only choice was to agree to the vaccine or to lose her job. Lala also noted:

> We are also afraid of accessing the COVID-19 vaccination. We are ordinary humans, we are afraid of taking the COVID-19 vaccine, but we need to take care of our own health.

Part of the reason that people do not trust the Indonesian government in terms of the COVID-19 response, is that health messages have been unclear and caused confusion. One of the impacts of a lack of trust in the government is that women are now deciding not to bring their children in for regular immunisations, such as for measles. Yana, a 24-year-old mother said:

> I decided not to immunise my second baby, who was born during this pandemic. I am afraid that the baby will not be given the regular immunisation, and I thought my child might be given the COVID-19 vaccine. For my older children who are school age, I will ask whether they will be vaccinated for COVID-19. If they tell me the children will be vaccinated for COVID-19, I will reject it for my children.

Figure 10: Social media message saying: “I am ready to be vaccinated” (Source: Ministry of Health Indonesia)

4. Belief in harmful side-effects and alternative ways of guarding against COVID-19

Some women noted that they did not want the vaccine because they were worried about adverse side effects, which were heightened among women who had comorbidities. Kanya, an HIV-positive mother told us: “I do not want to get vaccinated as I do not want to take any risks. I have asthma and HIV. I am afraid of disclosing my HIV status.”

Others mentioned fear of an allergic reaction. Some of the women noted disbelief that COVID-19 is real, or at least belief that COVID-19 poses no real health risk. For instance, Diah, a 29-year-old small shop owner noted: “People surrounding me did not believe in COVID-19, how come they want to access COVID-19 vaccines”.

Worry and disbelief play into the promotion of alternative ways of guarding against COVID-19. Some women talked about alternative ways of protecting themselves. For instance, Anti, a 49-year-old housewife said: “I do not want to take any risk [by having the vaccine]. I feel healthy and I am in a good condition. I just need to perform the health protocols [e.g. hand-washing] and maintain my immunity by taking vitamins. I also need to maintain my health by eating nutritional food. If I feel sick and suffer from COVID-19 symptoms, I just need to take vitamins and have a rest at home, it is easier (than getting vaccinated).”

Indonesia has a long way to go to gain public trust in its handling of COVID-19. There is little evidence that the government has implemented a national health solution, instead stoking public distrust through inconsistency and lack of transparency. To mitigate this doubt, the government should look to scientific evidence and effective communication, rather than coercive power and religious doctrine.

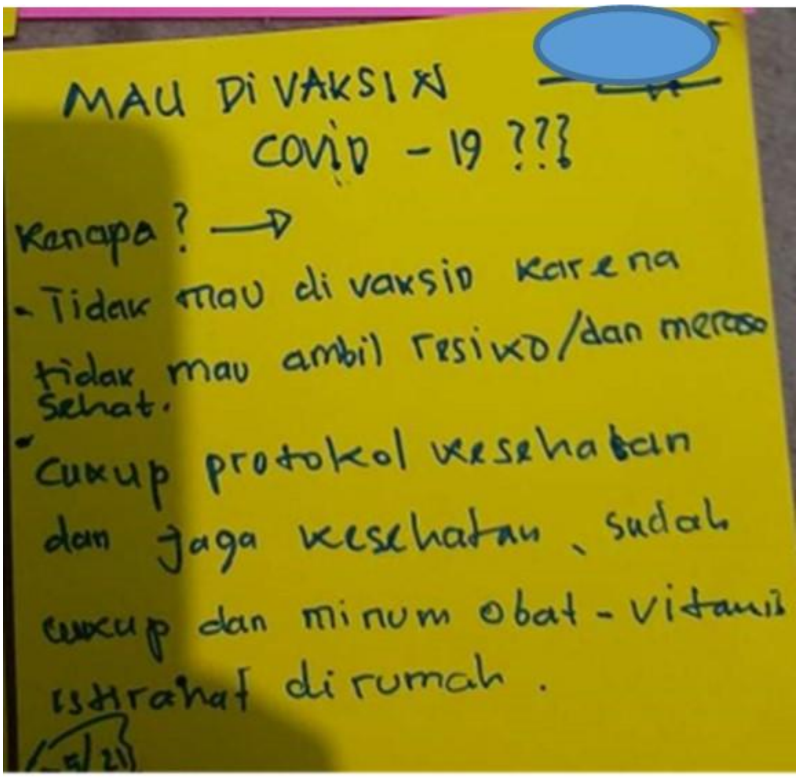
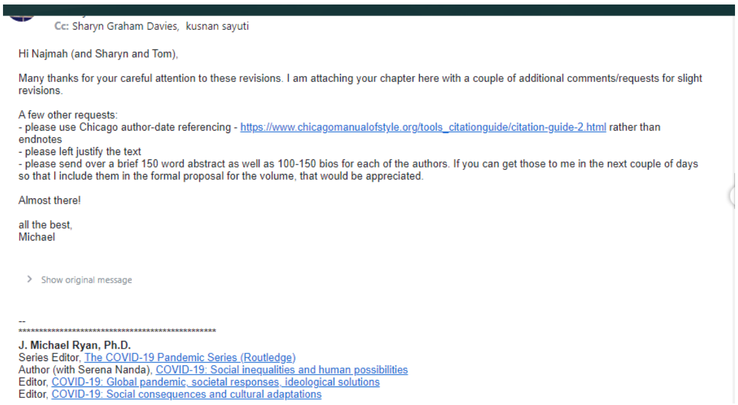


Figure 11: Mapping reasons women reject COVID-19. Source: Najmah (supplied by author)

Indonesia has a long way to go to gain public trust in its handling of COVID-19. There is little evidence that the government has implemented a national health solution, instead stoking public distrust through inconsistency and lack of transparency. To mitigate this doubt, the government should look to scientific evidence and effective communication, rather than coercive power and religious doctrine.

Chapter 6. Disclosing HIV Status during Indonesia's COVID-19 Pandemic: Challenges faced by mothers [26]


Cc: Sharyn Graham Davies, kusnan sayuti

Hi Najmah (and Sharyn and Tom),

Many thanks for your careful attention to these revisions. I am attaching your chapter here with a couple of additional comments/requests for slight revisions.

A few other requests:
- please use Chicago author-date referencing - https://www.chicagomanualofstyle.org/tools_citationguide/citation-guide-2.html rather than endnotes
- please left justify the text
- please send over a brief 150 word abstract as well as 100-150 bios for each of the authors. If you can get those to me in the next couple of days so that I include them in the formal proposal for the volume, that would be appreciated.

Almost there!

all the best,
Michael

Show original message

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****
J. Michael Ryan, Ph.D.
Series Editor, The COVID-19 Pandemic Series (Routledge)
Author (with Serena Nanda), COVID-19: Social inequalities and human possibilities
Editor, COVID-19: Global pandemic, societal responses, ideological solutions
Editor, COVID-19: Social consequences and cultural adaptations

Figure 12: Acceptance for this chapter in Routledge for the COVID-19 Pandemic Series

Introduction

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> My (HIV-positive) daughter, Via,[i] wants to be a police officer. She always mentions this ambition to her friends and teachers at school. But can she pursue this ambition? I am unsure (voice sobs). Via always asks me why she needs to take these medicines (Anti-Retroviral, ARV). Her questions make me sad. However I tell her it is our destiny; it is our fate (*sudah nasib kito*). We have to keep taking our ARV medicines, I tell her. I need to take mine too. I need to fight as I have six children. If I stop taking ARV medicines, I will pass away (*potos nyawo*). It would be a pity for my children.[ii] (Oneng, January 2021)

Oneng passed away from HIV complications (possibly COVID-19 related) in June 2021. As a widow, she left behind six children. She was the sole income earner, meaning that her children are now facing incredible financial hardship. When Oneng fell ill, she knew she should go to the hospital for treatment, but she was too afraid to go. She believedthat if she went to the hospital, she would

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[26] 2nd draft for submission in Routledge (book chapter), in collaboration with Najmah, Sharyn Graham Davies, Kusnan and Tom Graham Davies

contract COVID-19 and if she was hospitalised, she would be tested for COVID-19 and test positive. Oneng thus died at home, and the precise cause of death remains unknown.

Oneng's story of dying from HIV in a time of COVID-19 is not unexceptional in Indonesia. Widi, a pregnant woman living with HIV, shared a similar story. Like Oneng, Widi avoided visiting the hospital when she was ready to give birth for fear of contracting COVID-19. At any another time, Widi would have sought help from the Prevention of Mother-to-Child Transmission (PMTCT) services at her local public hospital. Widi knew that this service was the best way to avoid transmitting HIV to her unborn baby. Like Oneng, Widi believed that hospitals in the central city of Palembang which is also referral hospitals for COVID-19 patients in Indonesia are places where COVID-19 is spread. Widi thus gave birth to her baby at her local hospital in her village and disclose her HIV status .

Prior to COVID-19, both Oneng and Widi had for many years successfully managed their HIV using ARV and by accessing PMTCT services when delivering their babies. But the COVID-19 pandemic affected their desire to access such help. HIV-positive women are often afraid to go to the hospital because they know as people with underlying health conditions, COVID-19 is a particular threat to their well-being. But it is not just contracting COVID-19 that keeps HIV-mothers away from hospitals and ARV medications. These mothers are also afraid of disclosing their HIV status. With hospitals prioritising COVID-19 patients, disclosing one's HIV status can mean one is turned away from the hospital without treatment. As such, some HIV-positive women are delivering their babies in a hospital without disclosing their HIV status. They know this puts themselves, their baby, and the medical staff at risk but they see no other option to deliver their baby.

Parallels may be drawn between Oneng's and Widi's stories highlighting the cultural silence surrounding HIV in Indonesia, and how it intersects with COVID-19. For HIV-positive mothers who knew their HIV status during the pandemic, this late diagnosis of children's and mother's HIV status added additional burdens. Both HIV and COVID-19 are marked by a culture of denial, with governments, and even some health officials, downplaying their respective dangers. Sadly, this silence has resulted in increased suffering and preventable deaths. There is also a gendered aspect to this silence. For instance, popular narratives in Indonesia declare that 'good' wives and mothers do not get infected with HIV. As such, disclosing one's HIV status classifies a woman ipso facto as a ‘bad’ woman (e.g. someone who has had high-risk sexual intercourse and/or intravenous drug use)(Najmah 2019). This classification exacerbates the already tricky health and economic challenges experienced by women living with HIV. As such, some women ‘choose’ to stay silent about their HIV status to try and access pregnancy care. The culture of silence also feeds into and exacerbates fears of COVID-19, which are then compounded by the ill-treatment by health service providers of women living with HIV. The HIV-positive women we came to know during this research told us of their lives. Sadly, their stories include a great deal of suffering and economic struggle to meet daily necessities, as well as the institutionalised stigma of living with HIV in a time of COVID-19. This chapter thus examines how inequalities in gender and healthcare intersect with a lack of support services for women living with HIV to exclude women from the help they need. This chapter looks at two key themes. The first theme explores how COVID-19 increases the risk of death from HIV in Indonesia. The second theme investigates how the silence surrounding HIV results in the ill-treatment of HIV-positive women in health service settings. The methodology guiding the research was Feminist-Participatory Action Research. The focus of the research was marginalised HIV-positive women in South Sumatra, Indonesia. The research was conducted in December 2020 to August 2021.

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

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

During our interviews, from January to February 2021, Oneng spoke of the lack of support from health and NGO workers for her condition. In one instance, she expressed her frustration and anger when one NGO worker ignored her request for help to get ARV medication from the hospital. When her condition worsened, she sought a consultation during her monthly visit to the HIV centre in the public hospital. A worsening condition proved extremely challenging for her as restrictions in health facilities during the pandemic led to protocols that changed how doctors and patients interacted. The doctor she spoke to could not check her directly, kept a physical distance and only provided her with a prescription, and altered the combination of her ARVs to minimise their side effects. She added that some doctors who previously had roles in HIV treatment were employed elsewhere, treating COVID-19 patients, and were too busy to treat their regular HIV-positive patients. Therefore, Oneng delayed her much-needed hospitalisation, and resorted to self-treatment by combining herbal medicines with her ARVs. After feeling very sick, Oneng decided to visit the emergency room in the public hospital. Oneng revealed the following:

> *And right now, I feel sick because of increasing stomach acid. I was treated in an emergency room in a public hospital. Health workers provided quick treatment, therefore I was motivated to recover. Health workers knew I was HIV-positive, and I had to undergo some procedures, including two scans in the emergency room. Then, during my hospitalisation, I underwent two ultrasound checks. So many doctors cared for me, and I believe that that was the result of help from an HIV NGO who begged for me to be treated (Oneng's diary notes shared with the first author, April 2021)*

HIV-positive women in this study shared the struggle to get HIV care. HIV service provision decreased during the pandemic as medical resources were stretched. The alienation felt by women who were already subject to HIV-related stigma was worsened by protocols such as physical distancing between HIV-positive patients and doctors. In this instance, tables were used as barriers to minimise contact between HIV-positive women and health workers in Voluntary and Counselling Testing (VCT) because of COVID-19 concerns. Before pandemic, HIV-positive women can consult to the doctors without distance and sit closely in a counselling room. Even, the doctors who have been well-trained for HIV programmes provide friendly consultatation and do physical examination (Najmah Observation during PhD field work, 2017-2018). However, the condition was changed during pandemic.

With the shortage of health workers during the pandemic, well-trained HIV doctors who provided HIV therapy had to double their roles as general practitioners. Consequently, limited availability or access to HIV-related health specialists contributed to the reluctance of women living with HIV to get healthcare, even when they were feeling very sick.

> *The doctor who has a role in HIV treatment also has another role in mitigating COVID-19. Therefore, he was overworked and not able to give*

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

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

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

After Oneng's funeral, the first author visited Oneng's family. Her daughter explained that Oneng was not the only person to experience hardship because of medical resources being reallocated to fight COVID-19. Out of the six children, Ona was the only one who took care of her mother in the hospital and added how distressing it was to see her mother in such a state and on so many medications. Had she been given the attention she needed, it might have been avoided. "My mom took many medicines during her hospitalisation for her HIV, her toxoplasma and her gastritis" (Ona). Therefore, HIV-positive may suffer from HIV drug resistance as her ARV did not work well and lead to the opportunistic infection, like toxoplasmosis (Basavaraju 2021).As researchers, we directly experienced the hopelessness experienced by both affected individuals and its impact on their wider families. We use this to highlight the tension between the struggle to gain access to appropriate HIV care and the pain born by HIV-positive women caused by the re-tasking of medical professionals during the pandemic. Some young health workers who may not be well-train in deal with HIV-positive patients lead to reluctance of the patient to consult their poor health condition.

The above statement highlights the double burden of women living with HIV who have other underlying health conditions (opportunistic infection) experience, when subject to the negative consequences of COVID-19 related policies. These include perceived and real barriers to access health services during the pandemic. The combination of weakened immune systems along with the fear, and uncertainty of getting infected with COVID-19 from health facilities, results in fewer women seeking treatment and therefore lower life expectancy, as well as increasing the risk of wider HIV transmission (May 2017). Furthermore, the low economic status of women like Oneng is compounded by health disparities such as the non-availability of doctors for these groups (Chenneville et al. 2020). Worryingly, in some cases, self-treatment becomes the only perceived option for those who are too poor or too afraid to visit their health service providers when they have HIV. These barriers lead to delayed care-seeking and put a higher risk of death for women living with HIV.The Triple Bind of COVID-19 Restrictions

Covid-19 restriction were performed as strategies to reduce the spread of COVID-19. First, the government restrict the travel between region. Second, hospitals restrict health services to minimise COVID-19 transmission in health setting and shortages of health workers. Third, society restriction on avoiding hospital visit due to miss-information about every patient will be tested COVID-19 or will be diagnosed COVID-19. Unfortunately, these triple bind of COVID-19 restriction impact on the miss-opportunities to prevent HIV among mothers and children. HIV-positive mothers may not disclose their HIV services to get proper care. On the other hand, health workers may not conceal HIV status of HIV-positive mothers and children due to lack of professional health workers for HIV services.

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

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

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

COVID-19 also imposed a form of discrimination as Widi expressed that she feared breaking COVID-19 travel restrictions by accessing Preventing Mother-to-Child Transmission (PMTCT) HIV services in Palembang, a four-hour journey by car from where she lived.

> *I was initially hesitant to have my child, because I was afraid that I might transmit HIV to my baby. I was also fears of COVID-19 and travel restrictions from my village to Palembang. You know the pandemic is a difficult time for us (including economic challenges). There is an 80% chanceiii that my child would be infected with HIV. However, my husband supports me to treat our baby together if our baby gets HIV. (Widi, virtual interview)*

Based on a survey conducted by the Global Fund, from April to September 2020 across 502 health facilities in 32 countries in Asia and Africa, including Indonesia, there are several key reasons why people in this survey have tended to avoid visiting health services during the COVID-19 pandemic. Three main reasons include fear, mistrust, and uncertainty about the possibility of getting infected with COVID-19 from health services, limited public transportation due to mobility restriction, and the order of stay at home from the government.[iv] These perceived barriers were also found among 15 out of 20 HIV-positive women in this study and often resulted in non-disclosure of HIV status in health settings. Without proper sterilization and disinfectants and strict infection control and HIV therapy, the intersected elements of these barriers lead to miss-opportunities to prevent transmission to babies but also to other health workers and other patients.[v] The COVID-19 pandemic might also hinder ART continuation and PMTCT services access.[vi]

Covid-19 restriction also impact on non-concealment of HIV results to mothers and children in health setting. The disruption to HIV prevention services during the COVID-19 pandemic, including HIV screening for pregnant women, means more mothers are at a higher risk of not knowing their HIV status and more babies are at risk of potentially becoming infected with HIV (Jiang, Yi, and Weiming 2020). However, the silence surrounding HIV in health care settings means midwives and obstetricians often do not talk about HIV to pregnant patients. Consequently, not all midwives and obstetricians recommend that pregnant women do an HIV test, thus reinforcing the stigma. As a result, women may know their HIV after their children suffered from opportunistic infections, including malnutrition and was offered HIV test in hospital.

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

> The attending nurse explained that the Doctor who specialised in treating my daughter's condition, had other work to do and could not treat my daughter. Therefore, the hospital decided to refer my daughter to the public hospital. After arriving in the emergency room in the public hospital, the doctor explained the HIV status of my daughter (Nur, 2020).

After arriving at the public hospital, she recalled that a doctor called her into the emergency room, and as it was a crowded room, the doctor disclosed to Nur her child's

HIV positive status, with a low tone of voice in the corner of the room. “I was shocked to learn that she was infected with HIV” (Nur, interview).

Nur’s child is a saddening example of the late diagnosis of HIV. Though she accessed an obstetrician, an ante-natal clinic, and a midwifery practice, she was not offered an HIV test from 2017-2020. After experiencing three miscarriages, was offered a complete blood test, for which she paid about Rp 3,000,000 (about the US $210), but the tests was not included HIV-test. Free HIV-test for pregnant women is available in all public health services or puskesmas in Palembang, however not all pregnant women visit puskesmas for their antenatal check. Based on the survey, about 55% of all mothers go to private midwives who do not offer onsite HIV testing (Wulandari et al., 2019). In short, it took the length of her pregnancy and the child's current age, nearly oneand a half years, for the Indonesian health system to recognise the HIV positive status of a child borne by an HIV-positive mother. Nur’s story identified multifaceted barriers to accessing HIV treatment after her child has confirmed HIV-positive during the pandemic.

Health workers are also reluctant to discuss HIV as a stigma that may be attached to an institution. Health workers may attempt to protect the ‘good name’ of the hospital and choose to refer HIV positive patients to another specialist or hospital (Najmah 2019; The Global Fund 2021). Had Indonesia instituted a program to educate health care workers better, and work towards improved coordination between healthcare providers in the area of HIV, these issues and the suffering they cause, may well have been avoided. Like the previous research related to HIV-positive children during pandemic stated that “We cannot change the virus, but we can address their problems and ensure better living conditions”(pp 148) (Thomas, Sultanah, and Shahin 2020).

The silence surrounding HIV with the silence surrounding COVID-19

Silence is golden. It is common idioms that mean (saying) it is often best not to say anything(Oxford Learner’s Dictionary 2021). However, silence may not be golden if silence lead to people’s suffering and death. One of the most interesting finding in this study is the silencing surrounding HIV link the silence surrounding COVID-19. Manisfestation of intersectional these silencing, operated at mutifaceted elements: first: silencing and shame; second: silencing and morality; third: silencing and religious interpretation. Unfortunately, these silencing may contribute to delay health seeking behaviours, non-disclosure of HIV status by HIV-positive mothers and non-concealment of HIV status patient in health setting.

Notion of shame is a part of life in Indonesian and Muslim culture. Muslim is taught having a sense of shame, and being modest and shy is a part of faith (iman). In this study context, unfortunately, shame may prevent an individual from disclosing their HIV status, accessing health services and serving to psychologically imprison people (Hutchinson and Dhairyawan 2017). At individual level, women feel ashamed, dirty and not respected/needed and at community level, HIV is often seen as something people contract as punishment for acting immorally (Butt, 2015; Davies & Najmah, 2020). Therefore, silence is one means to ensure their motivation for living to avoid negative attitude or the access for a proper health services, particulary with the constraint health workers during pandemic. Interestingly, staying silent may be interpreted as acceptance of unfairness of health services as a destiny or takdir. The silence or absence of speech or quite, according to Picard, is necessarily related to divine and as metaphysics returns people to God and offers meta-or sub-discursive possibilities for understanding our world and about reality (need to parahprase) (Picard 1952).

The moral value is institutionalized in health services in Indonesia (Bennett, 2015, Butt, 2015). HIV-positive mothers, therefore, may lose regardless of the path they take in health services during pandemic: to be silence or not. Unprofessional attitudes can happen in health settings due to is not egalitarian and transparent communication between the patient and health worker (Bennet, 2015). This lack of transparancy is exacerbated by helplessness of health workers to separate the moral values that construct their perspective about HIV-positive women and the necessity to act professionally in carrying out their work. In any emergency situation, such as COVID-19 pandemic, prioritising health services for these marginalised groups are still taboo. The reasons may relate to release the professionality as a health workers and moral values as a human being as well as not to take the risks to contract HIV as well as COVID-19 (Davies and Najmah 2020). Therefore, it may result in organizational silence or systemised silence and ignorance that can be serve as threat for patient's health (Henriksen and Dayton 2006).

For instance, health worker who treated Nur's child with malnourished condition decided not to concel Nur's child HIV status and choose to refer the child to the public hospital. Oneng stayed silent on her worse health condition for a year, before accessing comprehensive health care for her complications due to distrust to health workers in related to unprofessional HIV consultation during pandemic. Another example, Widi decided not to disclose her HIV status as if she try to access care and declare her HIV status, she may be denied to deliver her baby in the hospital. However, the hospital also did not provide mandatory HIV test, as a part of regular blood testing before her delivery. In Indonesian idiom, it is known as 'buah simalakama' which mean that every way that HIV-positive women will choose, all will lead to negative response. We argue the silencing of HIV-positive mothers during pandemic is protest for their hopelessness to get fair health services. Unfortunately, the national health system is not fully protecting patients' right and limited universal precautions for health workers.

Conclusion

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

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

Finally, the sexually repressive culture espoused by the Indonesian government touches all aspects of how sexuality is expressed. From a health perspective, denial of sexuality-related issues serves only to undermine the physical and emotional health of Indonesians, resulting in easily avoidable hardship and shortened lifespans of a significant proportion of Indonesia's population.

5. Bibliography

AHF Indonesia. 2016. "Indonesia." https://www.aidshealth.org/global/Indonesia/.

AIDS and HIV Data Hub in ASIA Pacific. 2020. https://www.aidsdatahub.org/country-profiles/indonesia.

Anugerah, Pijar. 2021. "COVID: Mengapa Masih Ada Orang Yang Menyangkal Pandemi Maut Itu?" *BBC News Indonesia*, February 8, 2021. https://www.bbc.com/indonesia/majalah-58035319.

Badan Pusat Statistik. 2019. "Jakarta." https://www.bps.go.id/.

Basavaraju, Anuradha. 2021. "Toxoplasmosis in HIV Infection: An Overview." *Tropical Parasitology* 6 (2). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5048699/.

BBC News. 2021. "Delta Variant: Which Asian Countries Are Seeing Rising Cases?" *BBC News*, February 8, 2021. https://www.bbc.com/news/world-asia-53420537.

CEIC. 2019. "Indonesia Average Household Income: Palembang Municipality." Jakarta. https://www.ceicdata.com/en/indonesia/cost-of-living-survey-sbh2018-average-monthly-household-income-by-cities/average-household-income-palembang-municipality-other.

Chenneville, T, K Gabbidon, P Hanson, and C Holyfield. 2020. "The Impact of COVID-19 on HIV Treatment and Research: A Call to Action." *International Journal of Environmental Research and Public Health* 17 (12). https://www.mdpi.com/1660-4601/17/12/4548.

Chookajorn, T, T Kochakarn, C Wilasang, N Kotanan, and C Modchang. 2021. "Southeast Asia Is an Emerging Hotspot for COVID-19." *Nature Medicine*, no. 27 (August): 1495–96.

Citra Rosa, Maya. 2020. "PSBB Palembang Berakhir, Begini Komentar Dosen Epidemiologi Unsri Sebut Pandemi Corona Belum Selesai." *Sripoku*, June 17, 2020. https://palembang.tribunnews.com/2020/06/17/psbb-palembang-berakhir-begini-komentar-dosen-epidemiologi-unsri-sebut-pandemi-corona-belum-selesai.

Davies, Sharyn Graham, and Najmah. 2020. "Im/Moral Healthcare: HIV and Universal Health Coverage in Indonesia." *Sexual and Reproductive Health Matters* 28 (2). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7887970/.

Henriksen, K, and E Dayton. 2006. "Organizational Silence and Hidden Threats to Patient Safety." *Health Services Research* 41 (4): 1539–54.

Human Rights Watch. 2018. "'Scared in Public and Now No Privacy' Human Rights and Public Health Impacts of Indonesia's Anti-LGBT Moral Panic." New York, US. https://reliefweb.int/report/indonesia/scared-public-and-now-no-privacy-human-rights-and-public-health-impacts-indonesia-s.

Hutchinson, P, and R Dhairyawan. 2017. "Shame and HIV: Strategies for Addressing the Negative Impact Shame Has on Public Health and Diagnosis and Treatment of HIV." *Bioethics* 32 (1): 68–76.

Jiang, Hongbo, Zhou Yi, and Tang Weiming. 2020. "Maintaining HIV Care During the COVID-19 Pandemic." *The Lancet* 7 (5): e308–9.

Kompas. 2021. "Ini Perbedaan Aturan PPKM Level 1, 2, 3 Dan 4 Level 3," 2021. https://www.kompas.com/tren/read/2021/09/07/193000865/ini-perbedaan-aturan-ppkm-level-4-dan-level-3-.

Maguire, P. 1987. *Doing Participatory Research: A Feminist Approach*. Amherst MA: The Centre for International Education, University of Massachusetts.

May, Margaret T. 2017. "Better to Know: The Importance of Early HIV Diagnosis." *The Lancet Public Health* 2 (1): E6–7.

Miranda, V. 2011. "Cooking, Caring and Volunteering: Unpaid Work Around the World." 116. OECD Social, Employment and Migration Working Papers. OECD. https://www.oecd-ilibrary.org/social-issues-migration-health/cooking-caring-and-volunteering-unpaid-work-around-the-world_5kghrjm8s142-en.

Najmah. 2019. "My Baby Deserves Love, Not HIV Enabling. HIV-Positive Indonesian Women to Access Prevention of Mother-to-Child Transmission of HIV Services." Auckland, New Zealand: Auckland University of Technology.

Najmah, Sharyn Graham Davies, and Kusnan. 2021. "What Is Behind Vaccine Hesitancy in Indonesia?" *New Mandala New Perspectives on South East Asia*, May 25, 2021. https://www.newmandala.org/whats-behind-COVID-19-vaccine-hesitancy-in-indonesia/.

Najmah, Kusnan, Sari Andajan, Sharyn Graham Davies, and Tom Graham Davies. 2021. “COVID-19 Denial in Indonesia.” *Inside Indonesia*, June 6, 2021. https://www.insideindonesia.org/COVID-19-denial-in-indonesia.

Oxford Learner’s Dictionary. 2021. *Silence*. https://www.oxfordlearnersdictionaries.com/definition/english/silence_1.

Picard, Max. 1952. *The World of Silence*. H Regnery.

Putra, IGNE, D Astuti, DA Widyastari, and D Phuengsamran. 2018. “Prevalence and Feterminants of Condom Use Among Male Adolescents in Indonesia.” *International Journal of Adolescent Medicine and Health* 33 (29 November). https://doi.org/10.1515/ijamh-2018-0141.

Redaksi, Tim. 2020. “Mencatat Sejarah Tentang Respons Indonesia Hadapi COVID-19,” March. https://voi.id/bernas/4162/mencatat-sejarah-tentang-respons-indonesia-hadapi-COVID-19.

Sitorus, Ropesta. 2020. “Menteri Budi Karya Lama Sembuh Karena Dua Kali Positif COVID-19.” *Kabar24*, May 16, 2020. https://kabar24.bisnis.com/read/20200516/15/1241536/menteri-budi-karya-lama-sembuh-karena-dua-kali-positif-COVID-19-.

Statistics of Palembang. 2018.

The Global Fund. 2021. “The Impact of COVID-19 on HIV, TB and Malaria Services and Systems for Health.” https://www.theglobalfund.org/en/updates/other-updates/2021-04-13-the-impact-of-COVID-19-on-hiv-tb-and-malaria-services-and-systems-for-health/.

Thomas, R, A Sultanah, and Shahin. 2020. “Institutionalised Children With HIV AIDS During COVID-19 Pandemic A Case Study.” *International Journal of Social and Development Concersn*, no. Special issue social work during COVID-19.

UNAIDS. 2020. “Indonesia.” https://www.unaids.org/en/regionscountries/countries/indonesia.

US Aid. 2021. “Health.” https://www.usaid.gov/indonesia/health.

Volmink, JA. 2008. “HIV: Mother-to-Child Transmission.” *BMJ Clinical Evidence* 2008 (May). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2907958/#:~:text=Without%20antiviral%20treatment%2C%20the%20risk%20of%20transmission%20of,HIV-2%20is%20rarely%20transmitted%20from%20mother%20to%20child.

Wibawa, Tasha. 2019. “Indonesia Delays Plan to Ban Sex Out of Marriage and Limit Other Personal Freedoms.” *ABC News*, September 20, 2019. https://www.abc.net.au/news/2019-09-20/indonesia-set-to-outlaw-sex-before-marriage-affecting-tourists/11532328.

World Health Organization. 2015. "WHO Validates Elimination of Mother-to-Child Transmission of HIV and Syphilis in Cuba." https://www.who.int/news/item/30-06-2015-who-validates-elimination-of-mother-to-child-transmission-of-hiv-and-syphilis-in-cuba.

Yulius, Hendri. 2015. "Same-Sex Marriage in Indonesia." The University of Melbourne. https://indonesiaatmelbourne.unimelb.edu.au/same-sex-marriage-in-indonesia/.

Attachment 1: Ethical Approval from Sriwijaya University

ILMU ALAT PENGABDIAN

KOMISI ETIK PENELITIAN KESEHATAN
HEALTH RESEARCH ETHICS COMMITTEE
FAKULTAS KESEHATAN MASYARAKAT UNIVERSITAS SRIWIJAYA
FACULTY OF PUBLIC HEALTH SRIWIJAYA UNIVERSITY

KETERANGAN LOLOS KAJI ETIK
DESCRIPTION OF ETHICAL APPROVAL
"ETHICAL APPROVAL"

No : 002/UN9.FKM/TU.KKE/2021

Protokol penelitian yang diusulkan oleh :
The research protocol proposed by

Peneliti Utama : Najmah, S.K.M., M.P.H., PhD
Principal in Investigator

Nama Institusi : Fakultas Kesehatan Masyarakat Universitas Sriwijaya
Name of the Institution

Dengan Judul :
Tittle

"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 Concent, 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

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Indralaya, *January 4, 2021*
Head of the Committee,

KEPK-FKM

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

PEMERINTAH KOTA PALEMBANG
BADAN KESATUAN BANGSA DAN POLITIK KOTA PALEMBANG
JL. LUNJUK JAYA NOMOR - 3 DEMANG LEBAR DAUN PALEMBANG
TELPON (0711) 368726
Email : badankesbang@ yahoo.co.id

PALEMBANG DJAJA

Palembang, 19 Februari 2021

Nomor : 070/0326 /BAN.KBP/2021
Sifat : Biasa
Lampiran : -
Perihal : Izin Penelitian/Pengambilan Data

Kepada Yth.
1. Camat Seberang Ulu I Kota Palembang
2. Camat Seberang Ulu II Kota Palembang

di-
Palembang

Memperhatikan Surat Kepala Badan Kesatuan Bangsa dan Politik Provinsi Sumatera Selatan Nomor : 070 / 184/ Ban.KBP /2021 Tanggal 20 Januari 2021 perihal tersebut diatas, dengan ini diberitahukan kepada saudara bahwa:

No	*Nama*	*NIM/Universitas*	*Judul Penelitian*
1	*Najmah*	*Universitas Sriwijaya Palembang*	*Dites Atau Tidak : Sebuah Upaya Untuk Mengurangi Stigma Dalam Konteks Tes Covid-19 dan HIV di Indonesia (to get tested or not : A Project to reduce stigma around Covid-19 dan HIV testing in Indonesia).*

Untuk Melakukan Penelitian/Pengambilan Data
Masa Berlaku selama: 19 Februari 2021 s.d 19 Mei 2021

Dengan Catatan:

1. Sebelum melakukan penelitian/survey/riset/magang/KKN terlebih dahulu melapor kepada pemerintah setempat.
2. Penelitian tidak diizinkan menanyakan soal politik dan melakukan penelitian/survey/ riset yang sifatnya tidak ada hubungan dengan judul yang telah diprogramkan.
3. Dalam melakukan penelitian/survey/riset/magang/KKN agar dapat mentaati peraturan perundang-undangan dan adat istiadat yang berlaku di daerah setempat.
4. Apabila izin penelitian/survey/riset/magang/KKN telah habis masa berlakunya,sedang tugas penelitian/survey/riset/magang/KKN belum selesai maka harus perpanjangan izin
5. Setelah selesai mengadakan penelitian/survey/riset/magang/KKN diwajibkan memberikan laporan tertulis kepada Walikota Palembang melalui Kepala Badan Kesatuan Bangsa dan Politik Kota Palembang.

Demikian untuk dimaklumi dan untuk dibantu seperlunya.

a.n KEPALA BADAN KESATUAN BANGSA
DAN POLITIK KOTA PALEMBANG
KEPALA BIDANG IDEOLOGI,WAWASAN
KEBANGSAAN DAN KARAKTER BANGSA,

PEMERINTAH KOTA
BADAN KESATUAN BANGSA DAN POLITIK

SYAFRIL, S.Ag., M.Si
PENATA TINGKAT I
NIP 197606062001121005

Tembusan:
1. Kepala Badan Kesatuan Bangsa dan Politik Provinsi Sumatera Selatan;
2. Yang bersangkutan.

PEMERINTAH KOTA PALEMBANG

KECAMATAN SEBERANG ULU DUA

Jalan Jenderal A. Yani Kelurahan Empat - Belas Ulu Palembang,
Provinsi Sumatera Selatan Kode Pos 30264
Telepon : (0711) 513471 E-mail : su2.kec@gmail.com

Palembang, 19 Januari 2021

Nomor	: 070/093/SU DUA/2021	
Lampiran	: -	
Perihal	: Izin Penelitian/Pengambilan Data	

Kepada Yth,
Lurah Sebelas Ulu
Lurah Dua-Belas Ulu
Lurah Tiga-Belas Ulu
Lurah Empat-Belas Ulu
di-
PALEMBANG

Sehubungan Surat Universitas Sriwijaya Palembang Nomor : 0009/UN9.FKM/TU.SB.5/2021 tanggal 11 Januari 2021 Perihal: Izin Penelitian dengan ini pada prinsipnya kami tidak keberatan untuk memberikan izin atas nama :

No	Nama	Pekerjaan	Judul Penelitian
1.	Najmah,S.KM, M.PH. PhD	Dosen FKM. Unsri (Bagian Epidemiologi)	"Di tes atau tidak : sebuah upaya untuk mengurangi stigma dalam konteks tes Covid – 19 dan HIV Indonesia" (to get tested or not : A Project to reduce stigma around Covid – 19 dan HIV testing in Indonesia)

Untuk melakukan penelitian/pengambilan data
Lama penelitian tanggal ***07 Januari 2021 s/d 07 April 2021***.

Dengan Catatan:

1) Sebelum melakukan penelitian/survey/riset terlebih dahulu melaporkan kepada pemerintah setempat.
2) Penelitian tidak diizinkan menanyakan soal politik, dan melakukan penelitian/survey/riset yang sifatnya tidak ada hubungan dengan judul yang telah diprogramkan.
3) Dalam melakukan penelitian agar dapat mentaati peraturan perundang – undangan dan adat istiadat yang berlaku pada wilayah Kecamatan Seberang Ulu Dua Palembang
4) Apabila penelitian/survey/riset telah habis masa berlakunya, sedang tugas penelitian/survey/riset belum selesai maka harus ada perpanjangan izin.
5) Setelah melakukan penelitian diwajibkan memberikan laporan kepada Camat Seberang Ulu Dua Kota Palembang.

PEMERINTAH KOTA PALEMBANG KECAMATAN SEBERANG ULU DUA

CAMAT SEBERANG ULU DUA
KOTA PALEMBANG

RAKHMAN HIDAYAT PANE,S.STP
NIP. 198306092001121003

Attachment 2: Participants visual outcomes

1) <u>*Song by a group of Ibu rumah tangga who delivered baby during pandemic*</u>

Hai COVID
Hai COVID
Dia tidak mematikan
Jangan takut
Jangan ragu untuk tes COVID (2x)

Kalau mau sehat
Mari kita tes
Kita harus berani
Melakukan tesnya tidak sendiri
Dengan masyarakat tak perlu rasa takut

Hai COVID
Hai COVID
Dia tidak mematikan
Jangan takut
Jangan ragu kita harus sehat (2x)

Hai COVID
Hai COVID
Dia tidak mematikan
Dengan masyarakat melakukannya
Dengan senyum ceria
Indahnya apabila tes COVID gratis

Hey COVID, Hey COVID,
It's not deadly
Don't be afraid
Don't hesitate for COVID-test [2x]
If you want to be healthy,
Let's undertake test, we have to be brave,
We do the test not alone, but together with society
There is no need for fear of COVID-19
Hey COVID, Hey COVID
It's not deadly
With the community, doing it with a cheerful smile
That would be nice if the COVID-19 test is free

Video Link: https://www.youtube.com/watch?v=_eoXqicsKwI

2) <u>*Poem*</u>

<u>*Go Away HIV and COVID-19 (Enyahlah HIV dan COVID-19) (By Ibu Eds, HIV-positive mother)*</u>

Motherland....
I know the sky is cloudly and sad because of COVID-19 and HIV
Both are deadly But they transmitted in different ways

Motherland...
It doesn't feel it's been more than a year COVID-19 exists
It doesn't feel HIV is already exists on this earth for a long time
Go away COVID-19 Go away HIV
Don't stay in our hearts and minds
Motherland
Please be at peace with us in this time of the pandemic
Like HIV at peace with the world
Although painful discrimination is still attached COVID-19...
Please be at peace with health protocols
Motherland...
Never be afraid of COVID-19 and HIV Let's test ourselves
To ensure the health of our children and our family
Before it's too late
Let's do the test right now
Don't postpone it

Being a pregnant woman and a working woman during pandemic (Poem oleh Ibu W, a working mom)

I just realized the joy of life
When COVID was around
It turned out that
Everyone was afraid of sickness and death
I just realized the pleasure of working
When keeping distance is a key
So that everyone can avoid harm
I just realised the pleasure with family
When the policy of stay at home have to be enforced
Because everyone is busy taking care of themselves
I just realized the joy of being a mother
When I spent my 24 hours looking after my child
Because I don't want him to know how worried am I
I just realized the joy of being a wife
Because working at home, they thought I was on leave
Then, finally I asked myself "is it fair?"
I just realized the pleasure of eating a bowl of hot noodles
Because I am a mother and a lecturer at the same time
Make me to the point of insanity
But in the end
I have to keep in my mind His great blessings
I am a mother and a worker
Who gave birth during the pandemic
Video: https://www.youtube.com/watch?v=NZYRLLdo2hs

(Bahasa Indonesia)

Aku baru menyadari nikmatnya hidup
Ketika cobaan COVID ada di dunia ini

Ternyata semua orang takut akan sakit dan kematian

Aku baru menyadari nikmatnya bekerja
Ketika menjaga jarak menjadi kuncinya
Agar semua orang terhindari dari bahaya

Aku baru menyadari nikmatnya bersama keluarga
Ketika kebijakan dirumah saja harus dijalani
Karena semua orang menjaga diri

Aku baru menyadari nikmatnya menjadi ibu
Ketika 24 jam menjaga anakku
Karena tak ingin ia tau bagaimana khawatirnya aku

Aku baru menyadari nikmatnya menjadi istri
Karena bekerja di rumah aku dianggap sedang cuti
Hingga membuat aku bertanya adilkah ini

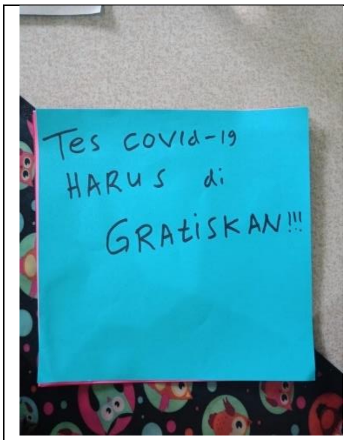
Aku baru menyadari nikmatnya semangkok mie rebus panas
Ketika menjadi ibu asuh dan ibu dosen dijalani bersamaan
Hingga membuat ku pada titik kegilaan

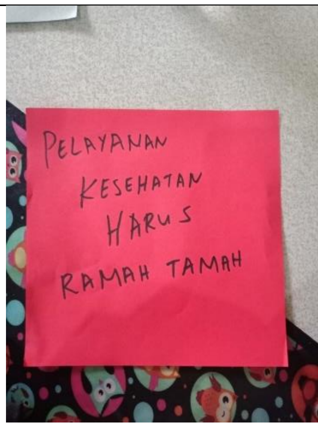
Namun pada akhirnya
Aku tetap harus menyadari nikmat-Nya yang begitu besar

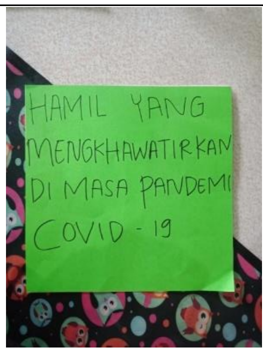
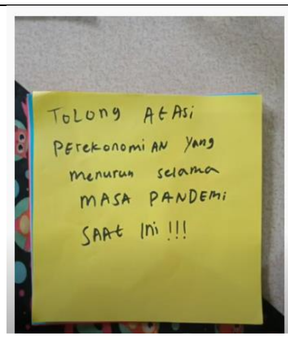
Aku, seorang...Ibu pekerja dan ibu yang melahirkan anak ketika pandemi

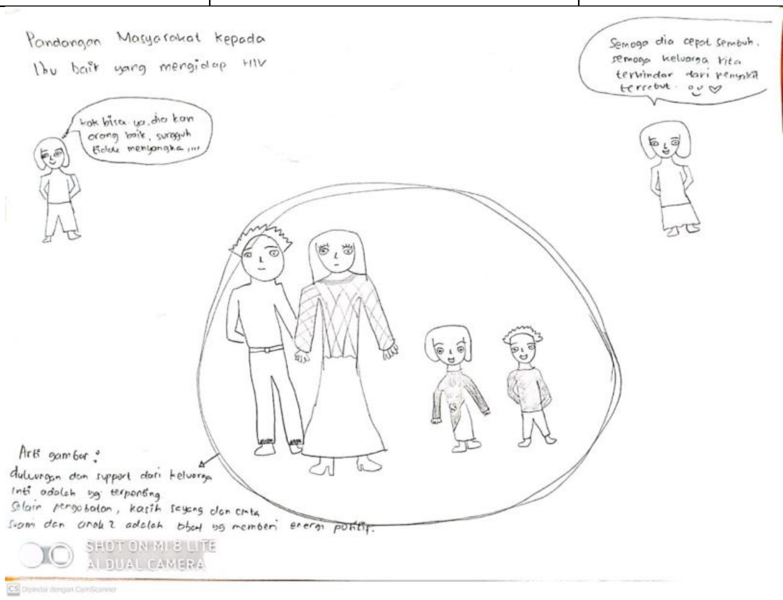
3) *<u>Visual Outcomes</u>*

<u>Mapping</u>







Perception of a good mothers and wives living with HIV
(Najmah documentation, drawing by Desi, mother with one, non HIV)

Person one : How come she could be infected with HIV, I don't really expect
Person two : I hope she would recover soon and our family would be protected from HIV
Family picture with cycle means there is the importance of nuclear family supports: affection from husband and kids create psychologycal support (medicine for positive energy) besides accessing biomedical medicines.

HIV and COVID-19 related stigma intersecting for mothers living with HIV

All three of us experienced different stigma
Some from family, doctors, society, friends, family, also ourselves
First Mom :
I'm mother who has two children
When i''m pregnant, I don't know that i am a mother with B20
Thank god, both my daughters are negative even though i am mother with B20
I was very sad when i found out that i have B20
But the doctor said that i was very great mother and very smart
Because i did the HIV test without prompting and being asked
Everything is based on what i want
I have never been afraid because i saw my little angle
I don't want them to get sick
I wanna see them all right
I am a great single mother
I am a single mother
I am single mother with good character
Second Mom :
I came to the hospital to give birth
And i said that i have B20
But i was considered as a bad woman
As if i was going to infect them, even though i was a good mother
And afraid to infect I had an unpleasant stigma
As if i'm going to transmit B20
Even though i told them about the disease i had, but i didn't get a good service i was even accused of being ba and having multiple partners
Whereas in my heart, i don't want to pass this B20 on to other mothers
I am the head of the family
Alhamdulillah, I really thank god
My three children are not infected and negative
3rd Mom :

I am a housewife with B20
I was stigmatized by them Even they are not infected
Even they are not infected
But they are affected by this stigma
Very painful for my children
We were excommunicated
Mocked, insulted, it hurts a lot
How to elimated stigma :
We have to strenghthen ourselves
With the support of a family, a great doctor, and the kids
We are a great mothers
A good mothers
And have a good character
For the sake of our children and our family
Those are some stigma that happened to mothers with B20(HIV)
Thank You We are great mothers who are strong and have a good character
Palembang, Febuary 2021
Source: Najmah's documentation (collage made by three HIV-positive mothers, February 2021)

Link video: *https://www.youtube.com/watch?v=MvuVKfqRvhw*

4) *Sample of Drama that was developed by Ibu rumah tangga who delivered baby during pandemic*

Link Video: https://www.youtube.com/watch?v=Ar8fey3YB00

Drama

Mrs. Yaya :moms, what are you guys talking about? It seems very exciting

Mrs. Devi :we are gossiping about COVID-19, not only gossiping about our household but also about COVID-19

Mrs. Yaya :is it about the difficulty of your childbirth?

Mrs. Devi : yeah, as usual
Mrs. Yaya : what's wrong?
Mrs. Devi : about the COVID-19 test, she said that there are health services that offer to test and some are not, but I am obliged
Mrs. Yaya : oh I wasn't even offered, so I didn't do the test
Mrs. Devi : how about you, mom?
Mrs. Jihan : I was offered but I was afraid, because if the result is positive then I have to be isolated, right?
Mrs. Yaya : yes, we need to think before doing the test, because we have children
Mrs. Devi : but I did the test and Alhamdulillah the result is negative, and then, I heard some issues said that we have to pay if we want to do COVID-19 test, is it right?
Mrs. Yaya : yeah, that's right, different clinics have different prices
Mrs. Devi : hmm I see, it means that it is not covered by BPJS right?
Mrs. Yaya : yeah I think so
Mrs. Devi : how about people who don't have the money to take a COVID-19 test if they are going to give birth?
Mrs. Yaya : that's what makes it difficult for society, the cost becomes a burden on the mind
Mrs. Devi : besides that our economy is in very downturn, right?, and then about the basic food problem
Mrs. Yaya : yeah, since the COVID-19 pandemic, salaries have been cut, shops have become quiet, so wages are reduced, things get harder
Mrs. Devi : What's your opinion of Indonesia?
Mrs. Yaya : it will be better if the COVID-19 test is free, although there's a fee, then it should not be expensive, it must be appropriate with the ability to pay of the society, don't make it harder. As we know, our income is decreases, while we spend a lot since we have children
Mrs. Devi : yeah that's right
Mrs. Yaya : to buy milk, pampers, we need money to buy it right?, instead of using the money to do a COVID-19 test, it's better to use them for our children need
Mrs. Devi : How about you? What do you think about the cost of the COVID-19 test?
Ibu Jihan : yeah I hope that the test is free, as well as medical services at the hospital should be made easier, don't be complicated
Mrs. Devi : as usual, we are mothers who like freebies
Mrs. Yaya : and then, hospital services to patients who pay with BPJS and out of pocket payments should not be differentiated, we are also patients. Just because it's free they can be unkind to us, they seem like want to angry with us, while patients with out of pocket payments are served very well and friendly, they treated us very different. It shouldn't be like that right?
Mrs. Devi : What are your hopes for Indonesia during this COVID-19 pandemic?
Mrs. Yaya : I hope that the test is free, the government provide basic foodstuffs to the community
Mrs. Devi : I agree
Mrs. Yaya : if once a month is too frequent, then once every two months is okay. And it will be better if they provide discounts for electricity and water payments, it will help a little
Mrs. Devi : and I heard that the cost of electricity and water has gone up, right?

Mrs. Jihan	: yeah that’s right
Mrs. Yaya	: yeah, that’s right, our bills also became expensive
Mrs. Devi	: same, my bills have also become expensive, even though we don’t use that much
Mrs. Yaya	: yeah
Mrs. Devi	: so, what is the solution to our economic problems? While their side seemed to close their eyes
Mrs. Yaya	: yeah, I don’t know when this pandemic will end. Hopefully it can be handled as soon as possible
Mrs. Yaya	: yeah
Mrs. Devi	: without any tests, and it will be easier for pregnant women. If there are pregnant women who mwant to give birth at midnight and there are no doctors or nurses, it will be difficult
Mrs. Jihan	: yeah
Mrs. Yaya	: that’s right
Mrs. Devi	: we used to be without fear. By the way, let’s end our conversation today because I want to cook and take care of my child
Mrs. Yaya	: yeah, let’s meet up again soon
Mrs. Devi	: bye~

AUSTRALIAN INVOLVEMENT IN ALUMNI GRANT SCHEME-ROUND 2

AUSTRALIAN AWARDS FOR INDONESIA

Project title:

To get tested or not: A project to reduce stigma around COVID-19 and HIV testing in Indonesia

Najmah, PhD

Associate Prof Sharyn Graham Davies

Faculty of Public Health, Sriwijaya University

Herb Feith Indonesia Engagement Centre,

Monash University

Alumni Grant Scheme-Round 2

2020-2021

Authors' Bio

Najmah, PhD

Najmah is a lecturer in the Public Health Faculty of Sriwijaya University, South Sumatra, Indonesia. Najmah was awarded a prestigious New Zealand Scholarship for her doctoral studies and graduated from Auckland University of Technology in 2020. She completed her PhD under the supervision of Dr Sari Andajani and Associate Professor Sharyn Davies, whilst looking after her three toddlers. Najmah also has degrees from the University of Melbourne, where she studied with an AusAID Partnership Scholarship, and her bachelor degree in Sriwijaya University (Unsri), South Sumatra. Najmah is the author of four books of Epidemiology and Biostatistics and an editor of three books related to Data analysis and research methodology in Public Health and English camps in Indonesia. She is currently writing her fifth book in qualitative approach and enthusiasm in Feminist and Participatory Action Research. Najmah's research interest is HIV, women and COVID-19. (email: najem240783@yahoo.com/najmah@fkm.unsri.ac.id/instagram: najmah.usman.7)

Associate Professor Dr Sharyn Graham Davies

Sharyn Graham Davies is Director of the Herb Feith Indonesia Engagement Centre and Associate Professor in the School of Languages, Literatures, Cultures and Linguistics at Monash University in Melbourne, Australia. She received her PhD from the University of Western Australia (Anthropology and Asian Studies) and prior to her appointment at Monash was at Auckland University of Technology (AUT) in New Zealand. Sharyn has held visiting fellowships at Cambridge, Yale, Sydney, Peking and Airlangga universities, and has been awarded Fulbright, Leverhulme and Marsden funding. Sharyn is recognised internationally as an expert in the field of Indonesian Studies and for her contributions to the study of gender, sexuality, policing, social media, and moral surveillance.

1. Writing a manuscript for Book chapter in ROUTLEDGE publisher

Proof of Acceptance of our manuscript

The book chapter will be published on March 2022

Proposal for Edited Volumes

COVID-19: Volume III: Cultural Change and Institutional Adaptations

COVID-19: Volume IV: Individual Rights and Community Responsibilities

COVID-19: Volume V: Surviving a Pandemic

Edited by:

J. Michael Ryan, Ph.D.
Assistant Professor of Sociology
Nazarbayev University

COVID-19: Volume V: Surviving a Pandemic

Chapter 9: Disclosing HIV Status during Indonesia's COVID-19 Pandemic: challenges faced by mothers

Najmah (Sriwijaya University), Kusnan (INCIEF Malaysia), Sharyn Graham Davies (Monash University), Tom Graham Davies (Independent Scholar)

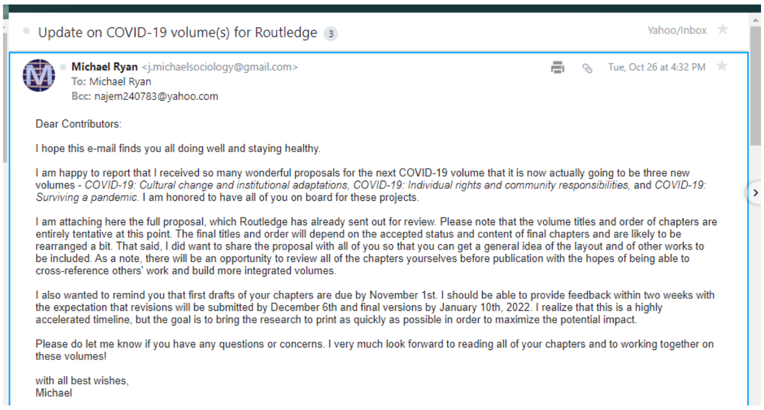
Abstract:

Prior to COVID-19, many mothers in Indonesia successfully managed their HIV. They were able to source required medications, and when pregnant, they were able to access Prevention of Mother to Child Transmission services to decrease the chance of transmitting HIV to their baby. However, the COVID-19 pandemic has affected the ability of mothers to access HIV care for two primary reasons. First, many HIV-positive mothers are now afraid to go to a hospital (for care or even for collecting medicine) because hospitals are considered places where people get infected with COVID-19. Second, mothers are afraid of disclosing their HIV status when giving birth because hospitals are prioritising COVID-19 patients, and disclosing one's HIV status, even when in labour, could mean you are turned away from the hospital. As such, some HIV-positive mothers are delivering their babies in hospitals without disclosing their HIV status. A culture of silence thus pervades the intersection of HIV and COVID-19, with Indonesian society yet to have an open discussion about the interplay between these two diseases.

This chapter explores the stories of three mothers living with HIV as they navigate Indonesia's COVID-19 pandemic. The chapter reveals that mothers lose regardless of the path they take: if they stay away from medical care to avoid contracting COVID-19 they may die; if they try to access care and declare their HIV status, they may be denied care; if they access care and do not declare their HIV status, they cannot access the HIV treatment that keeps them and their children alive. In addition, the stigma attached to HIV and the lack of HIV tests during the pandemic has resulted in miss-opportunities to diagnosed HIV among pregnant women in health services.

<u>Proof of Corresponding with editor of Routledge book and Monash University</u>

1. Acceptance of our team manuscript



Update on COVID-19 volume(s) for Routledge 3 Yahoo/Inbox

Michael Ryan <j.michaelsociology@gmail.com> Tue, Oct 26 at 4:32 PM
To: Michael Ryan
Bcc: najem240783@yahoo.com

Dear Contributors:

I hope this e-mail finds you all doing well and staying healthy.

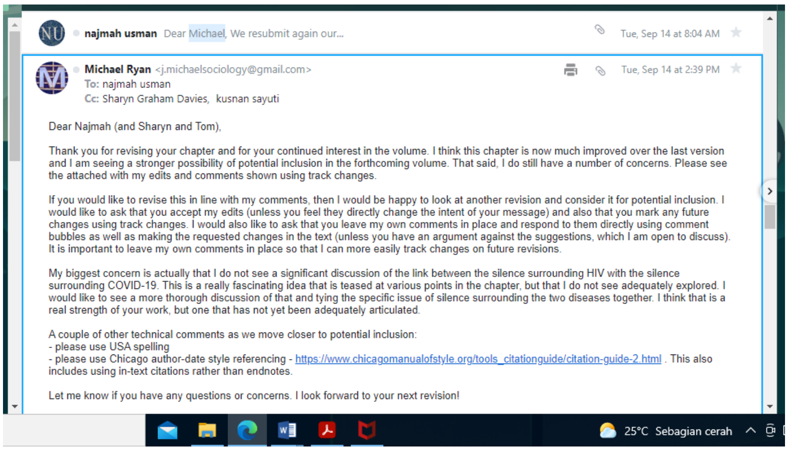
I am happy to report that I received so many wonderful proposals for the next COVID-19 volume that it is now actually going to be three new volumes - *COVID-19: Cultural change and institutional adaptations*, *COVID-19: Individual rights and community responsibilities*, and *COVID-19: Surviving a pandemic*. I am honored to have all of you on board for these projects.

I am attaching here the full proposal, which Routledge has already sent out for review. Please note that the volume titles and order of chapters are entirely tentative at this point. The final titles and order will depend on the accepted status and content of final chapters and are likely to be rearranged a bit. That said, I did want to share the proposal with all of you so that you can get a general idea of the layout and of other works to be included. As a note, there will be an opportunity to review all of the chapters yourselves before publication with the hopes of being able to cross-reference others' work and build more integrated volumes.

I also wanted to remind you that first drafts of your chapters are due by November 1st. I should be able to provide feedback within two weeks with the expectation that revisions will be submitted by December 6th and final versions by January 10th, 2022. I realize that this is a highly accelerated timeline, but the goal is to bring the research to print as quickly as possible in order to maximize the potential impact.

Please do let me know if you have any questions or concerns. I very much look forward to reading all of your chapters and to working together on these volumes!

with all best wishes,
Michael



najmah usman Dear Michael, We resubmit again our... Tue, Sep 14 at 8:04 AM

Michael Ryan <j.michaelsociology@gmail.com> Tue, Sep 14 at 2:39 PM
To: najmah usman
Cc: Sharyn Graham Davies, kusnan sayuti

Dear Najmah (and Sharyn and Tom),

Thank you for revising your chapter and for your continued interest in the volume. I think this chapter is now much improved over the last version and I am seeing a stronger possibility of potential inclusion in the forthcoming volume. That said, I do still have a number of concerns. Please see the attached with my edits and comments shown using track changes.

If you would like to revise this in line with my comments, then I would be happy to look at another revision and consider it for potential inclusion. I would like to ask that you accept my edits (unless you feel they directly change the intent of your message) and also that you mark any future changes using track changes. I would also like to ask that you leave my own comments in place and respond to them directly using comment bubbles as well as making the requested changes in the text (unless you have an argument against the suggestions, which I am open to discuss). It is important to leave my own comments in place so that I can more easily track changes on future revisions.

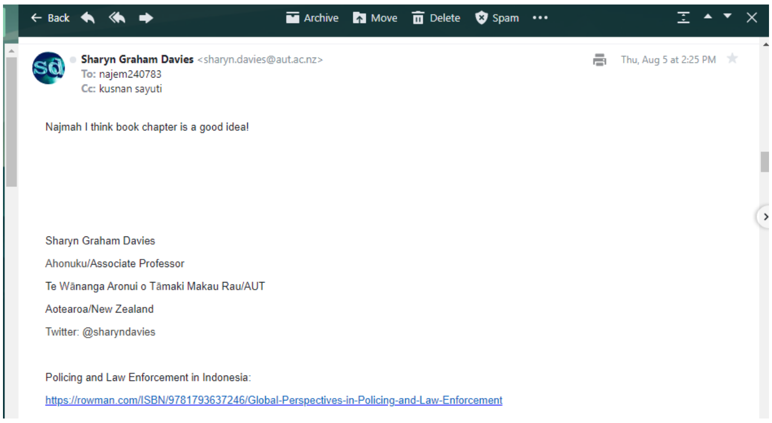
My biggest concern is actually that I do not see a significant discussion of the link between the silence surrounding HIV with the silence surrounding COVID-19. This is a really fascinating idea that is teased at various points in the chapter, but that I do not see adequately explored. I would like to see a more thorough discussion of that and tying the specific issue of silence surrounding the two diseases together. I think that is a real strength of your work, but one that has not yet been adequately articulated.

A couple of other technical comments as we move closer to potential inclusion:
- please use USA spelling
- please use Chicago author-date style referencing - https://www.chicagomanualofstyle.org/tools_citationguide/citation-guide-2.html . This also includes using in-text citations rather than endnotes.

Let me know if you have any questions or concerns. I look forward to your next revision!

25°C Sebagian cerah

2. Discussion with Sharyn Graham Davies about book chapter writing, consultation and editting



Back Archive Move Delete Spam

Sharyn Graham Davies <sharyn.davies@aut.ac.nz> Thu, Aug 5 at 2:25 PM
To: najem240783
Cc: kusnan sayuti

Najmah I think book chapter is a good idea!

Sharyn Graham Davies

Ahonuku/Associate Professor

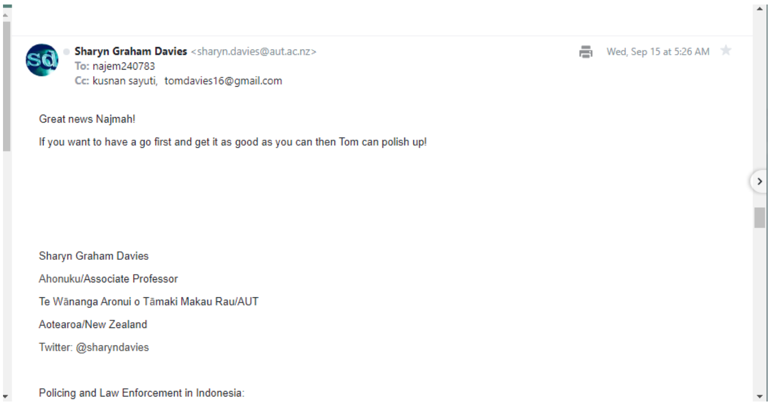
Te Wānanga Aronui o Tāmaki Makau Rau/AUT

Aotearoa/New Zealand

Twitter: @sharyndavies

Policing and Law Enforcement in Indonesia:

https://rowman.com/ISBN/9781793637246/Global-Perspectives-in-Policing-and-Law-Enforcement



Sharyn Graham Davies <sharyn.davies@aut.ac.nz>
To: najem240783
Cc: kusnan sayuti, tomdavies16@gmail.com

Wed, Sep 15 at 5:26 AM

Great news Najmah!

If you want to have a go first and get it as good as you can then Tom can polish up!

Sharyn Graham Davies

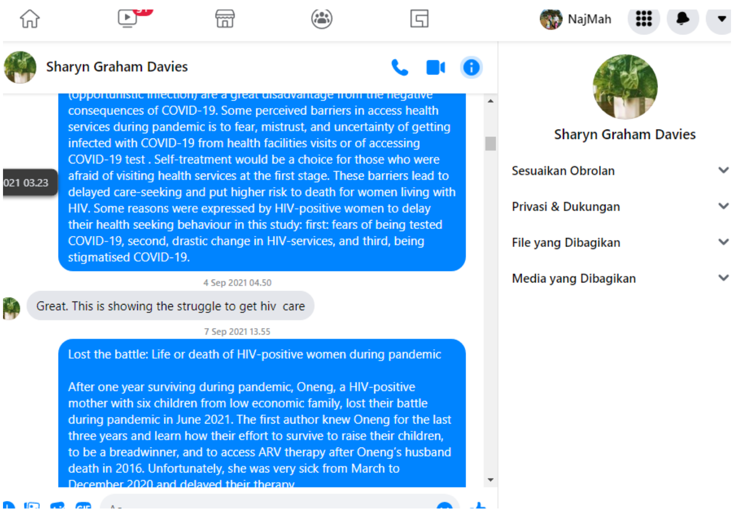
Ahonuku/Associate Professor

Te Wānanga Aronui o Tāmaki Makau Rau/AUT

Aotearoa/New Zealand

Twitter: @sharyndavies

Policing and Law Enforcement in Indonesia:



NajMah

Sharyn Graham Davies

(opportunistic infection) are a great disadvantage from the negative consequences of COVID-19. Some perceived barriers in access health services during pandemic is to fear, mistrust, and uncertainty of getting infected with COVID-19 from health facilities visits or of accessing COVID-19 test . Self-treatment would be a choice for those who were afraid of visiting health services at the first stage. These barriers lead to delayed care-seeking and put higher risk to death for women living with HIV. Some reasons were expressed by HIV-positive women to delay their health seeking behaviour in this study: first: fears of being tested COVID-19, second, drastic change in HIV-services, and third, being stigmatised COVID-19.

021 03.23

4 Sep 2021 04.50

Great. This is showing the struggle to get hiv care

7 Sep 2021 13.55

Lost the battle: Life or death of HIV-positive women during pandemic

After one year surviving during pandemic, Oneng, a HIV-positive mother with six children from low economic family, lost their battle during pandemic in June 2021. The first author knew Oneng for the last three years and learn how their effort to survive to raise their children, to be a breadwinner, and to access ARV therapy after Oneng's husband death in 2016. Unfortunately, she was very sick from March to December 2020 and delayed their therapy

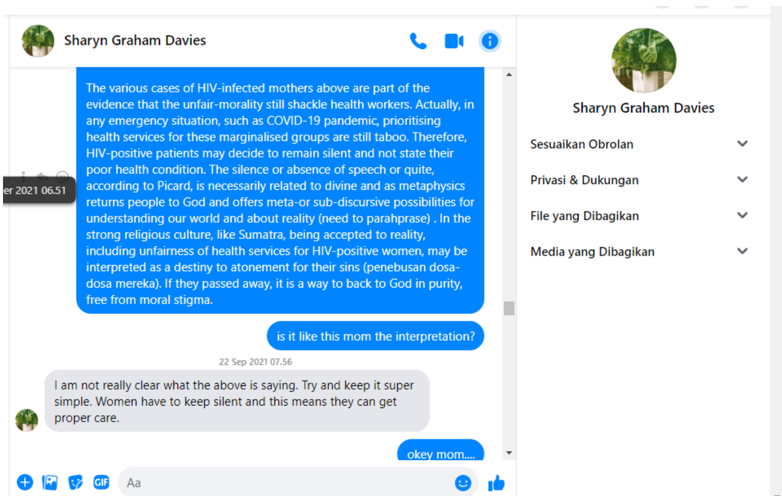
Sharyn Graham Davies

Sesuaikan Obrolan

Privasi & Dukungan

File yang Dibagikan

Media yang Dibagikan



Sharyn Graham Davies

The various cases of HIV-infected mothers above are part of the evidence that the unfair-morality still shackle health workers. Actually, in any emergency situation, such as COVID-19 pandemic, prioritising health services for these marginalised groups are still taboo. Therefore, HIV-positive patients may decide to remain silent and not state their poor health condition. The silence or absence of speech or quite, according to Picard, is necessarily related to divine and as metaphysics returns people to God and offers meta-or sub-discursive possibilities for understanding our world and about reality (need to parahprase) . In the strong religious culture, like Sumatra, being accepted to reality, including unfairness of health services for HIV-positive women, may be interpreted as a destiny to atonement for their sins (penebusan dosa-dosa mereka). If they passed away, it is a way to back to God in purity, free from moral stigma.

er 2021 06.51

is it like this mom the interpretation?

22 Sep 2021 07.56

I am not really clear what the above is saying. Try and keep it super simple. Women have to keep silent and this means they can get proper care.

okey mom....

Aa

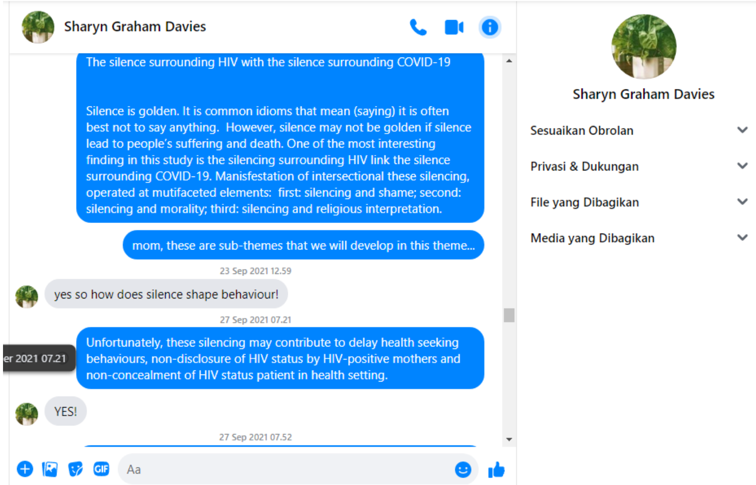
Sharyn Graham Davies

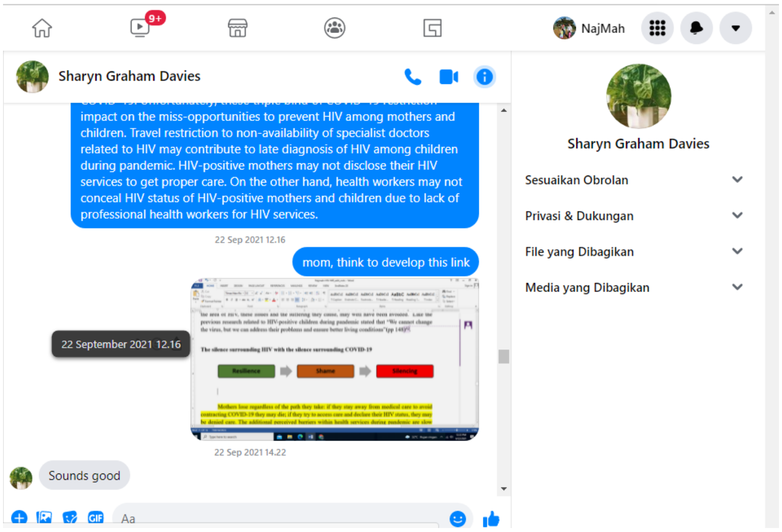
Sesuaikan Obrolan

Privasi & Dukungan

File yang Dibagikan

Media yang Dibagikan





<u>Final manuscript draft (Introduction and conclusion)</u>

Disclosing One's HIV Status during Indonesia's COVID-19 Pandemic:

Challenges faced by mothers

Najmah, Kusnan, Tom Graham Davies, Sharyn Graham Davies

Abstract

Prior to the COVID-19 pandemic, available data suggests nearly three out of ten mothers in Indonesia were successfully managing their HIV (Human Immunodeficiency Virus) (UNAIDS Indonesia 2020). These mothers were able to source required medications, and when pregnant, were able to access Prevention of Mother to Child Transmission services to decrease the chance of transmitting HIV to their babies. However, the COVID-19 pandemic affected the ability of mothers to access HIV care in two primary ways. First, many HIV-positive mothers became fearful of going to hospital (for care or even to collect medicine) because hospitals became places where people got infected with COVID-19. Second, mothers were afraid of disclosing their HIV status when giving birth because hospitals were at capacity and disclosing one's HIV status, even when in labor, could mean the hospital refused treatment due to the perceived added resources needed. Knowing this possibility, some HIV-positive mothers delivered their babies in hospital without disclosing their HIV status. A culture of silence pervades the intersection of HIV and COVID-19, and Indonesian society is yet to have an open discussion about the interplay between these two diseases.

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

Conclusion

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

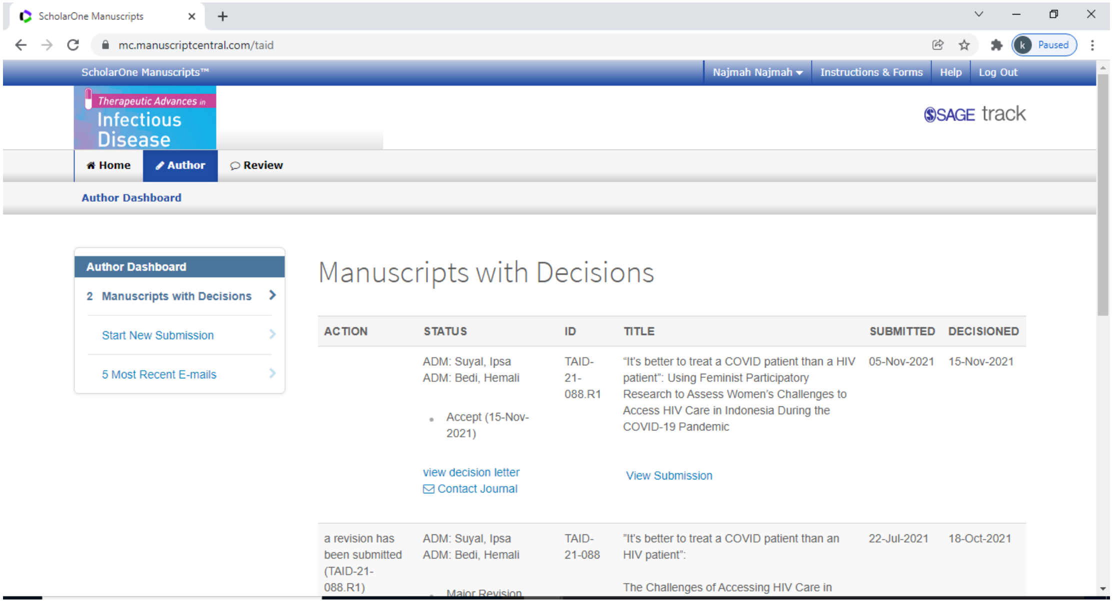
What lessons can be learnt from this research? Late diagnosis and testing of both HIV and COVID-19 reflect institutional and cultural barriers which surround the treatment of HIV in the era of COVID-19. They suggest an interplay of inadequate communication and coordination between levels of government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

Acknowledgements
We are extremely grateful to the HIV-positive women who helped us in this study. Thank you to our research assistant, Nadilla Nusirwan, Happy Mira Jordanti, Andita Eka Putri , Riska Isnaini and Erni Wahyuni. Also thank you for the research grant from Alumni Grant Scheme Round 2, Australian Awards for Indonesia, 2020-2021. Thank you for Monash University and Sriwijaya University for supporting this research.

2. Writing a manuscript for Therapeutic Advances in Infectious Disease

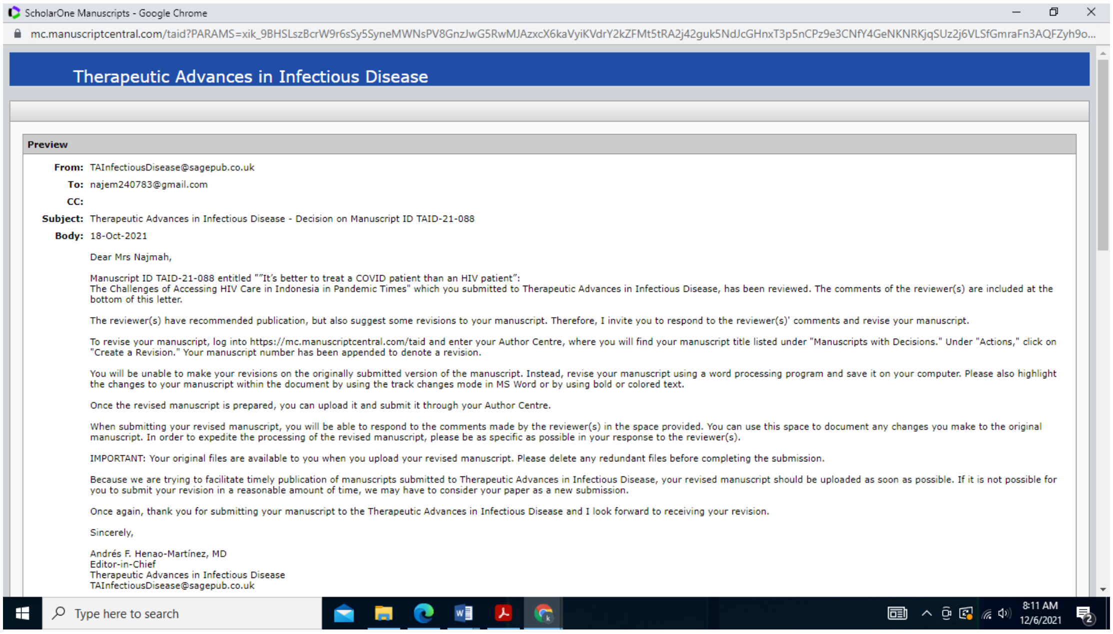
<u>*Proof of Acceptance of our manuscript*</u>

The manuscript will be published on December 2021



Manuscripts with Decisions

ACTION	STATUS	ID	TITLE	SUBMITTED	DECISIONED
	ADM: Suyal, Ipsa ADM: Bedi, Hemali • Accept (15-Nov-2021) view decision letter Contact Journal	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 View Submission	05-Nov-2021	15-Nov-2021
a revision has been submitted (TAID-21-088.R1)	ADM: Suyal, Ipsa ADM: Bedi, Hemali • Major Revision	TAID-21-088	"It's better to treat a COVID patient than an HIV patient": The Challenges of Accessing HIV Care in	22-Jul-2021	18-Oct-2021



Therapeutic Advances in Infectious Disease

Preview

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 Mrs Najmah,

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

Proof of Corresponding with Sharyn Graham Davies from Monash University

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From: najmah usman <najem240783@yahoo.com>
Sent: Tuesday, 29 June 2021 12:11 AM
To: Sharyn Graham Davies <sharyn.davies@aut.ac.nz>
Subject: Special Collection on HIV and Women's Health: Where Are We Now?, due 1 October 2021

Special Collection on HIV and Women's Health: Where Are We Now?

To have your paper considered for this Special Collection, submit by October 1, 2021.

Please review the Manuscript Submission Guidelines before submitting your paper.

Click here to submit your paper.

Guest Editors

Dr Shema Tariq, *Institute for Global Health, University College London, London, UK*
Bakita Kasadha, *University of Oxford, Oxford, UK*

Overview

Women make up over half the global population of people living with HIV, with trans women 49 times more likely to be living with HIV than other adults of reproductive age. However, only 25% of HIV clinical trial participants are

ckTag)

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Sharyn Graham Davies <sharyn.davies@aut.ac.nz> Thu, Jul 1 at 12:19 PM
To: najem240783

Hi, I can make time to proof read this one if you're submitting to this special issue.

Let me know!

Sharyn Graham Davies
Ahonuku/Associate Professor
Te Wānanga Aronui o Tāmaki Makau Rau/AUT
Aotearoa/New Zealand
Twitter: @sharyndavies

Policing and Law Enforcement in Indonesia:
https://rowman.com/ISBN/9781793637246/Global-Perspectives-in-Policing-and-Law-Enforcement

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Sharyn Graham Davies <sharyn.davies@aut.ac.nz> Mon, Jul 5 at 6:50 AM
To: najem240783, Najmah Unsri

Lovely!

I've done a bit of cleaning up.

You could send to the editors and see if they have any initial comments on it??

Cheers

Sharyn

Sharyn Graham Davies
Ahonuku/Associate Professor
Te Wānanga Aronui o Tāmaki Makau Rau/AUT
Aotearoa/New Zealand

From: najmah usman <najem240783@yahoo.com>
Sent: Wednesday, 7 July 2021 1:10 AM
To: Najmah Unsri <najmah@fkm.unsri.ac.id>; Sharyn Graham Davies <sharyn.davies@aut.ac.nz>
Subject: {Spam?} Re: Special Collection on HIV and Women's Health: Where Are We Now?, due 1 October 2021

Dear Mom

I add Tiki and Nur's story, who raised HIV-positive children and need to access health services during a pandemic. Interestingly, both of them experienced less stigma and considered health workers were friendly to treat their children. Though, some health workers still asked them how come they got infected with HIV

Najmah

On Monday, July 5, 2021, 04:36:20 PM GMT+7, najmah usman <najem240783@yahoo.com> wrote:

Thank you mom for your help

Final manuscript draft (Introduction and conclusion)

Therapeutic Advances in Infectious Disease

"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

Journal:	*Therapeutic Advances in Infectious Disease*
Manuscript ID	TAID-21-088.R1
Manuscript Type:	Original Manuscript
Date Submitted by the Author:	05-Nov-2021
Complete List of Authors:	Najmah, Najmah; Sriwijaya University, Public Health; Kampung Pandai 13 Ulu, Social and Education Davies, Sharyn ; Monash University, Director Herb Feith Indonesia Engagement Centre Kusnan, Kusnan; INCEIF, Islamic Economic Davies, Tom; Monash University, Social Science
Keywords:	
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

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.

11. Conflict of Interest

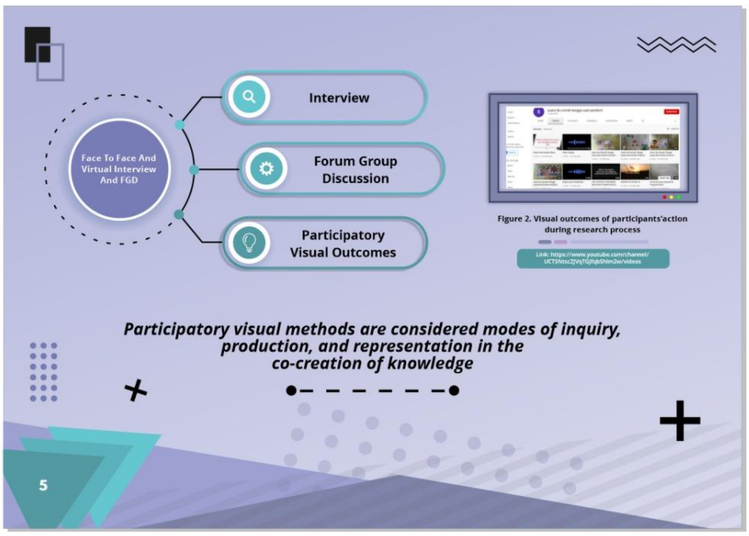
None to declare

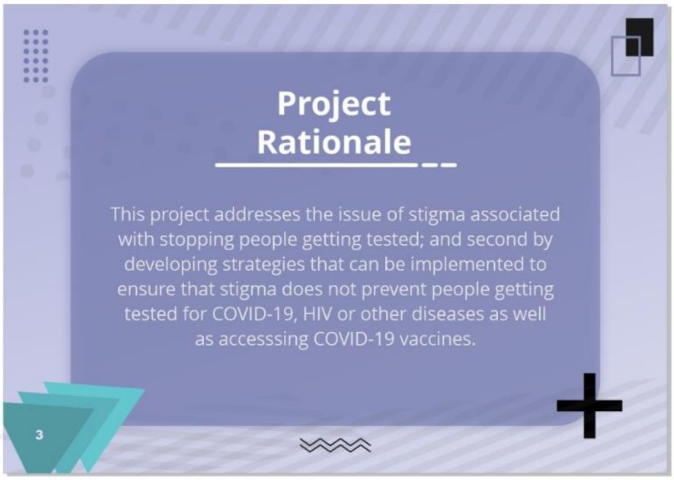
12. Funding statement

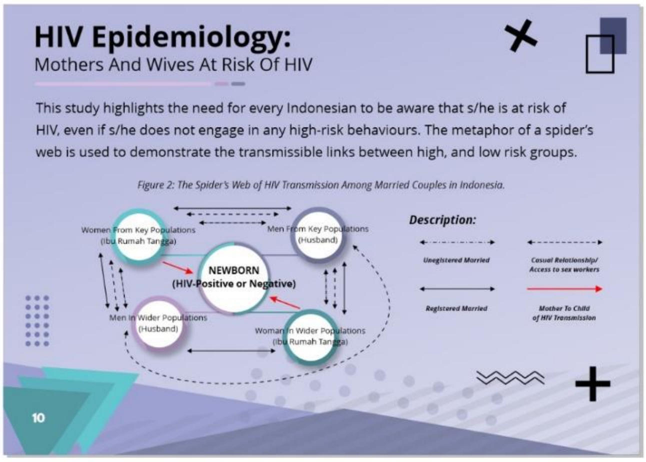
Alumni Grant Scheme (AGS) Round 2, Australian Award for Indonesian. Available on https://www.australiaawardsindonesia.org/project/detail/189/15/to-get-tested-or-not-a-project-to-reduce-stigma-around-Covid-19-and-hiv-testing-in-indonesia

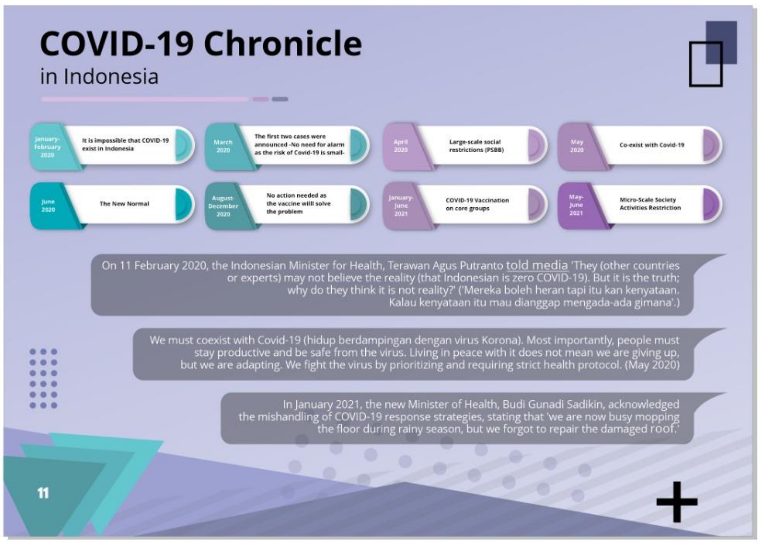
3. Booklet Development for dissemination

<u>*Booklet draft*</u>

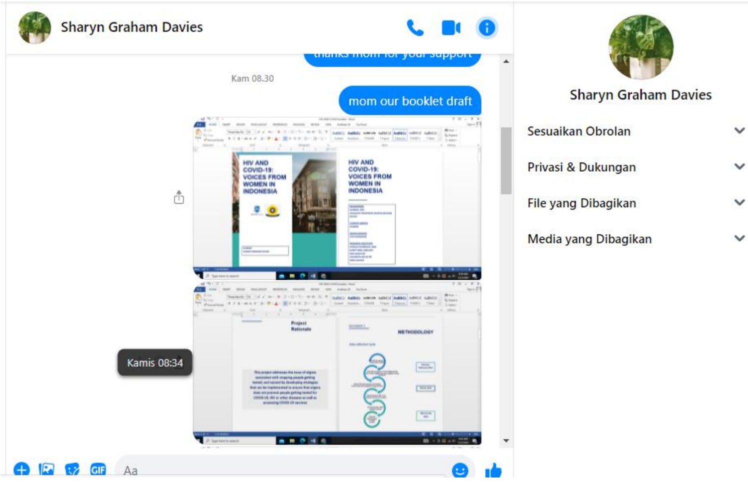


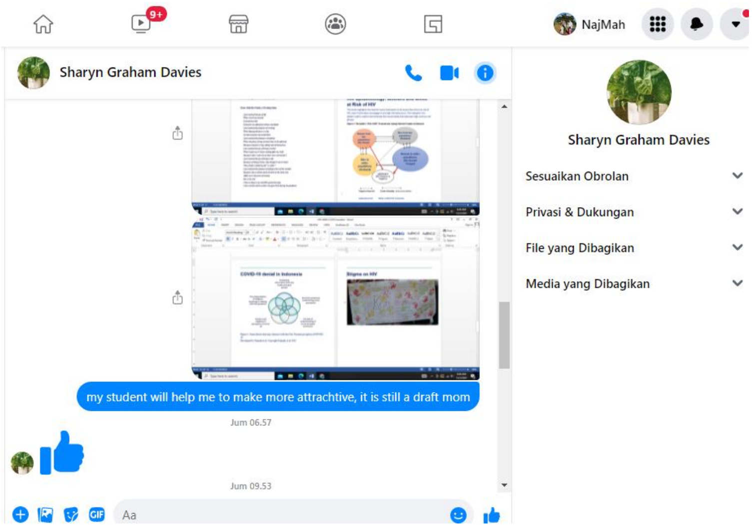

Project
Rationale
This project addresses the issue of stigma associated with stopping people getting tested; and second by developing strategies that can be implemented to ensure that stigma does not prevent people getting tested for COVID-19, HIV or other diseases as well as accesssing COVID-19 vaccines.
3

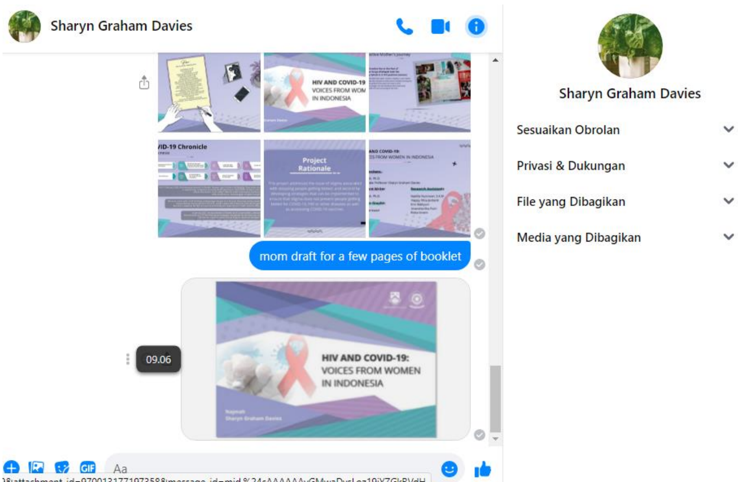

HIV Epidemiology:
Mothers And Wives At Risk Of HIV
This study highlights the need for every Indonesian to be aware that s/he is at risk of HIV, even if s/he does not engage in any high-risk behaviours. The metaphor of a spider's web is used to demonstrate the transmissible links between high, and low risk groups.
Figure 2: The Spider's Web of HIV Transmission Among Married Couples in Indonesia.
Women From Key Populations (Ibu Rumah Tangga)
Men From Key Populations (Husband)
NEWBORN (HIV-Positive or Negative)
Men In Wider Populations (Husband)
Woman In Wider Populations (Ibu Rumah Tangga)
Description:
Unegistered Married
Casual Relationship/ Access to sex workers
Registered Married
Mother To Child of HIV Transmission
10


COVID-19 Chronicle
in Indonesia
January-February 2020
It is impossible that COVID-19 exist in Indonesia
March 2020
The first two cases were announced -No need for alarm as the risk of Covid-19 is small-
April 2020
Large-scale social restrictions (PSBB)
May 2020
Co-exist with Covid-19
June 2020
The New Normal
August-December 2020
No action needed as the vaccine willl solve the problem
January-June 2021
COVID-19 Vaccination on core groups
May-June 2021
Micro-Scale Society Activities Restriction
On 11 February 2020, the Indonesian Minister for Health, Terawan Agus Putranto told media 'They (other countries or experts) may not believe the reality (that Indonesian is zero COVID-19). But it is the truth; why do they think it is not reality?' ('Mereka boleh heran tapi itu kan kenyataan. Kalau kenyataan itu mau dianggap mengada-ada gimana'.)
We must coexist with Covid-19 (hidup berdampingan dengan virus Korona). Most importantly, people must stay productive and be safe from the virus. Living in peace with it does not mean we are giving up, but we are adapting. We fight the virus by prioritizing and requiring strict health protocol. (May 2020)
In January 2021, the new Minister of Health, Budi Gunadi Sadikin, acknowledged the mishandling of COVID-19 response strategies, stating that 'we are now busy mopping the floor during rainy season, but we forgot to repair the damaged roof.'
11

Proof of Corresponding with Sharyn Graham Davies from Monash University







Thank you

Alumni Grant Scheme Round 2