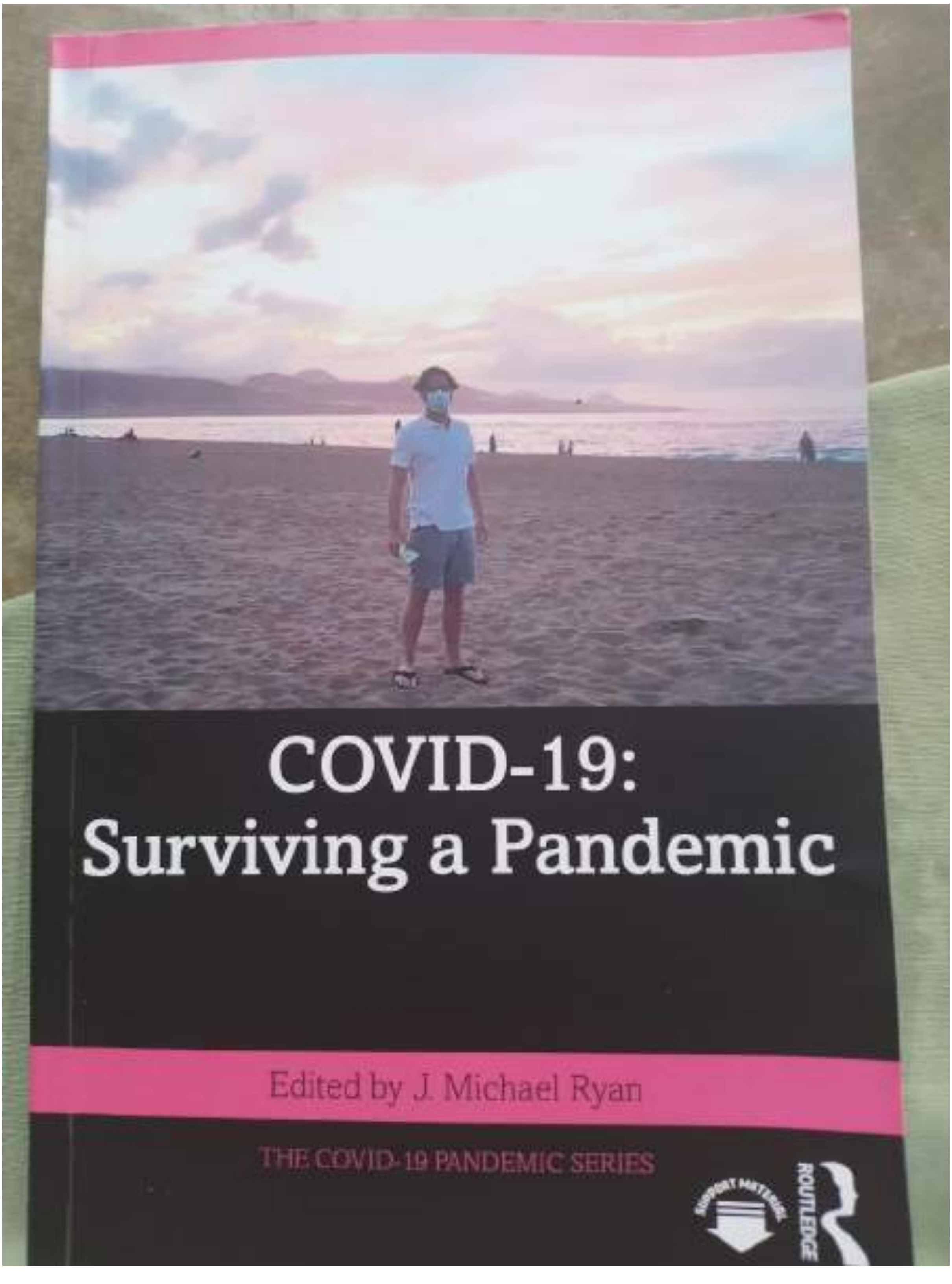


COVID-19: Surviving a Pandemic

Edited by J. Michael Ryan

THE COVID-19 PANDEMIC SERIES

[Cover]

COVID-19: SURVIVING A PANDEMIC

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

A central question since this pandemic began has been how to survive it. This question has applied not just to staying alive, but also to staying healthy, both physically and mentally. Survival is certainly key, but surviving, and what that means, is also critical. The scholarship included in this volume will take a closer look at what it means to survive by addressing such issues as the importance of ethnicity in vaccine uptake, the gendered and racialized impacts of the pandemic, the impact on those with disabilities, questions of food security, and what it means to grieve.

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

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

[Prakata]

Cover image: © J. Michael Ryan

First published 2023
by Routledge
4 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

and by Routledge
605 Third Avenue, New York, NY 10158

Routledge is an imprint of the Taylor & Francis Group, an informa business

British Library Cataloguing-in-Publication Data
A catalogue record for this book is available from the British Library

Library of Congress Cataloging-in-Publication Data
Names: Ryan, J. Michael, editor.
Title: COVID-19 : surviving a pandemic / edited by J. Michael Ryan.
Description: Abingdon, Oxon ; New York, NY : Routledge, 2023. | Includes bibliographical references and index.
Identifiers: LCCN 2022031009 (print) | LCCN 2022031010 (ebook) | ISBN 9781032299167 (hardback) | ISBN 9781032299174 (paperback) | ISBN 9781003302698 (ebook)
Subjects: LCSH: COVID-19 Pandemic, 2020—Social aspects. | COVID-19 Pandemic, 2020—Psychological aspects.
Classification: LCC RA644.C67 C45226 2023 (print) | LCC RA644.C67 (ebook) | DDC 362.1962/4144—dc23/eng/20220912
LC record available at https://lccn.loc.gov/2022031009
LC ebook record available at https://lccn.loc.gov/2022031010

ISBN: 978-1-032-29916-7 (hbk)
ISBN: 978-1-032-29917-4 (pbk)
ISBN: 978-1-003-30269-8 (ebk)

DOI: 10.4324/9781003302698

Typeset in Bembo
by Apex CoVantage, LLC

Access the Support Material: https://www.routledge.com/9781032299174

ndividuals,
scientific
related to
than a
medical
current
s series

Creative Resilience and COVID-19
Figuring the Everyday in a Pandemic
Edited by Irene Gammel and Jason Wang

COVID-19 and Childhood Inequality
Edited by Nazneen Khan

The Color of COVID-19
The Racial Inequality of Marginalized Communities
Edited by Sharon A. Navarro and Samantha L. Hernandez

COVID-19, Communication and Culture
Beyond the Global Workplace
Edited by Fiona Rossette-Crake and Elvis Buckwalter

Social and Political Representations of the COVID-19 Crisis
Daniel Feierstein

Playful Pedagogy in the Pandemic
Pivoting to Games-Based Learning
Emily K. Johnson and Anastasia Salter

COVID-19 and Social Change in Spain
Edited by Carlos de Castro, Andrés Pedreño and Marta Latorre

COVID-19: Cultural Change and Institutional Adaptations
Edited by J. Michael Ryan

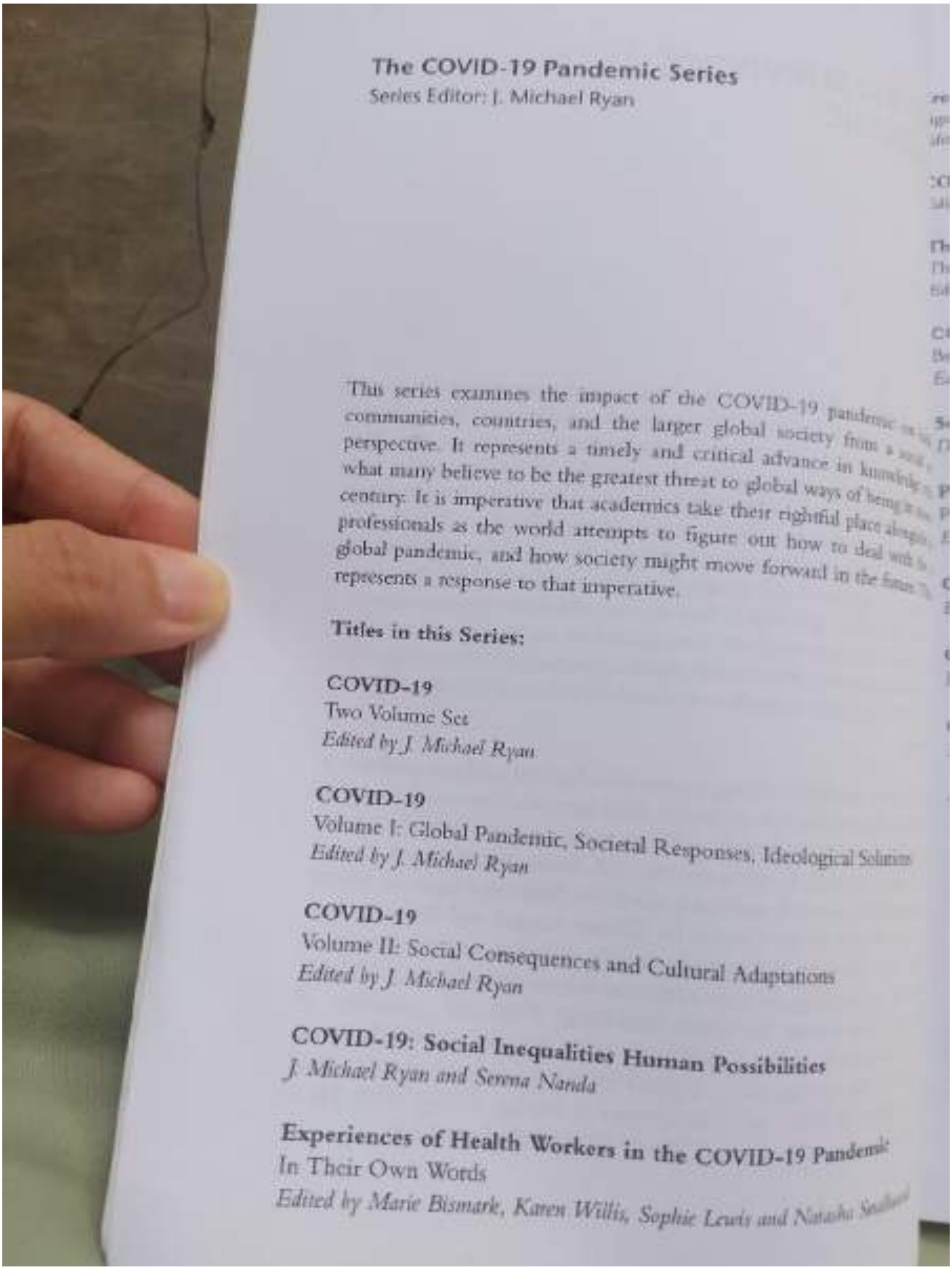
COVID-19: Individual Rights and Community Responsibilities
Edited by J. Michael Ryan

COVID-19: Surviving a Pandemic
Edited by J. Michael Ryan

Pandemic Pedagogies
Teaching and Learning during the COVID-19 Pandemic
Edited by J. Michael Ryan

COVID-19 in Brooklyn
Everyday Life During a Pandemic
Jerome Krase and Judith DeSena

The Pandemic in Britain
COVID-19, British Exceptionalism and Neoliberalism
Sean Creaven



The COVID-19 Pandemic Series
Series Editor: J. Michael Ryan

This series examines the impact of the COVID-19 pandemic on communities, countries, and the larger global society from a perspective. It represents a timely and critical advance in knowledge what many believe to be the greatest threat to global ways of being in the century. It is imperative that academics take their rightful place alongside professionals as the world attempts to figure out how to deal with global pandemic, and how society might move forward in the future represents a response to that imperative.

Titles in this Series:

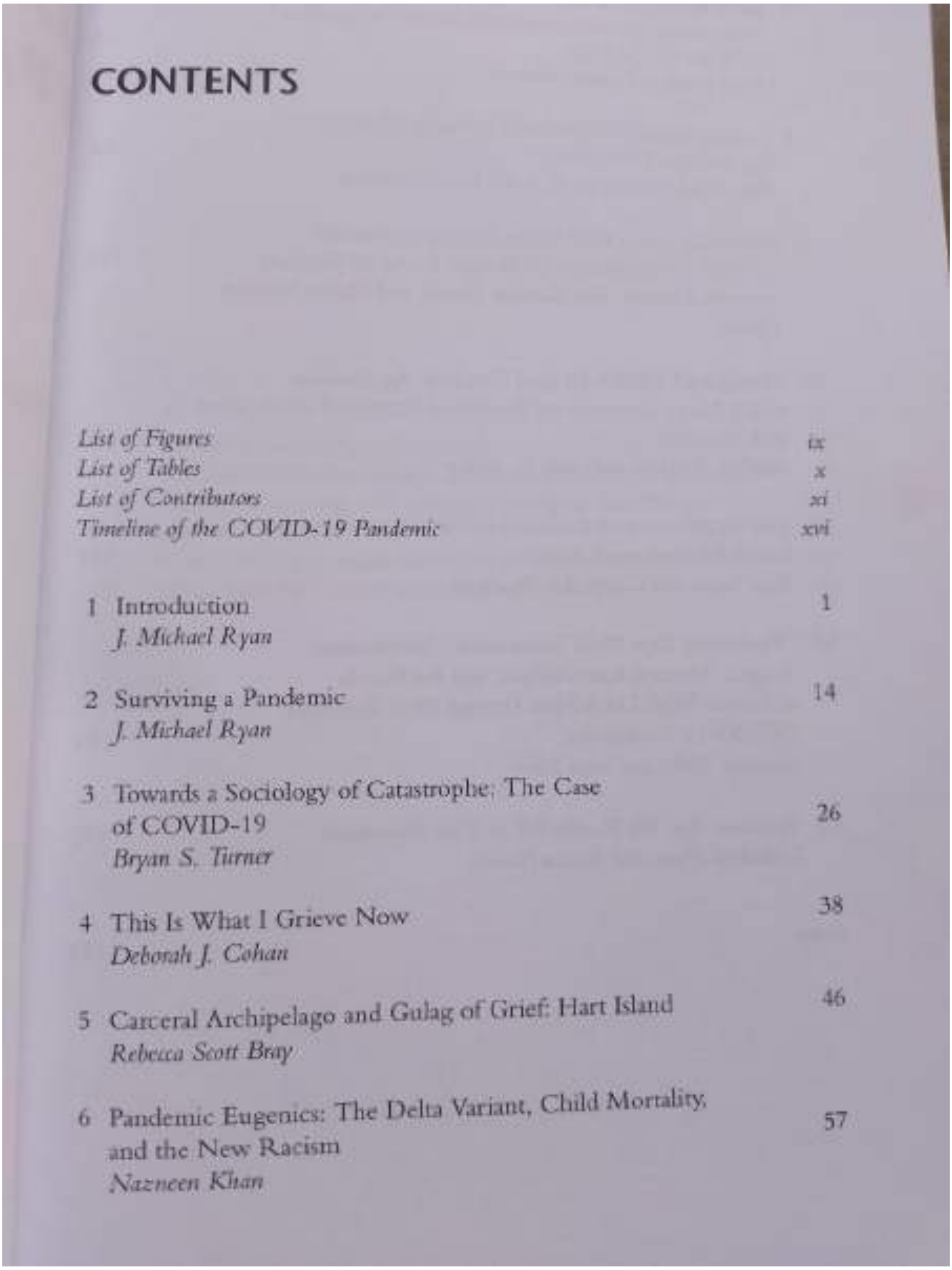
COVID-19
Two Volume Set
Edited by J. Michael Ryan

COVID-19
Volume I: Global Pandemic, Societal Responses, Ideological Solutions
Edited by J. Michael Ryan

COVID-19
Volume II: Social Consequences and Cultural Adaptations
Edited by J. Michael Ryan

COVID-19: Social Inequalities Human Possibilities
J. Michael Ryan and Serena Nanda

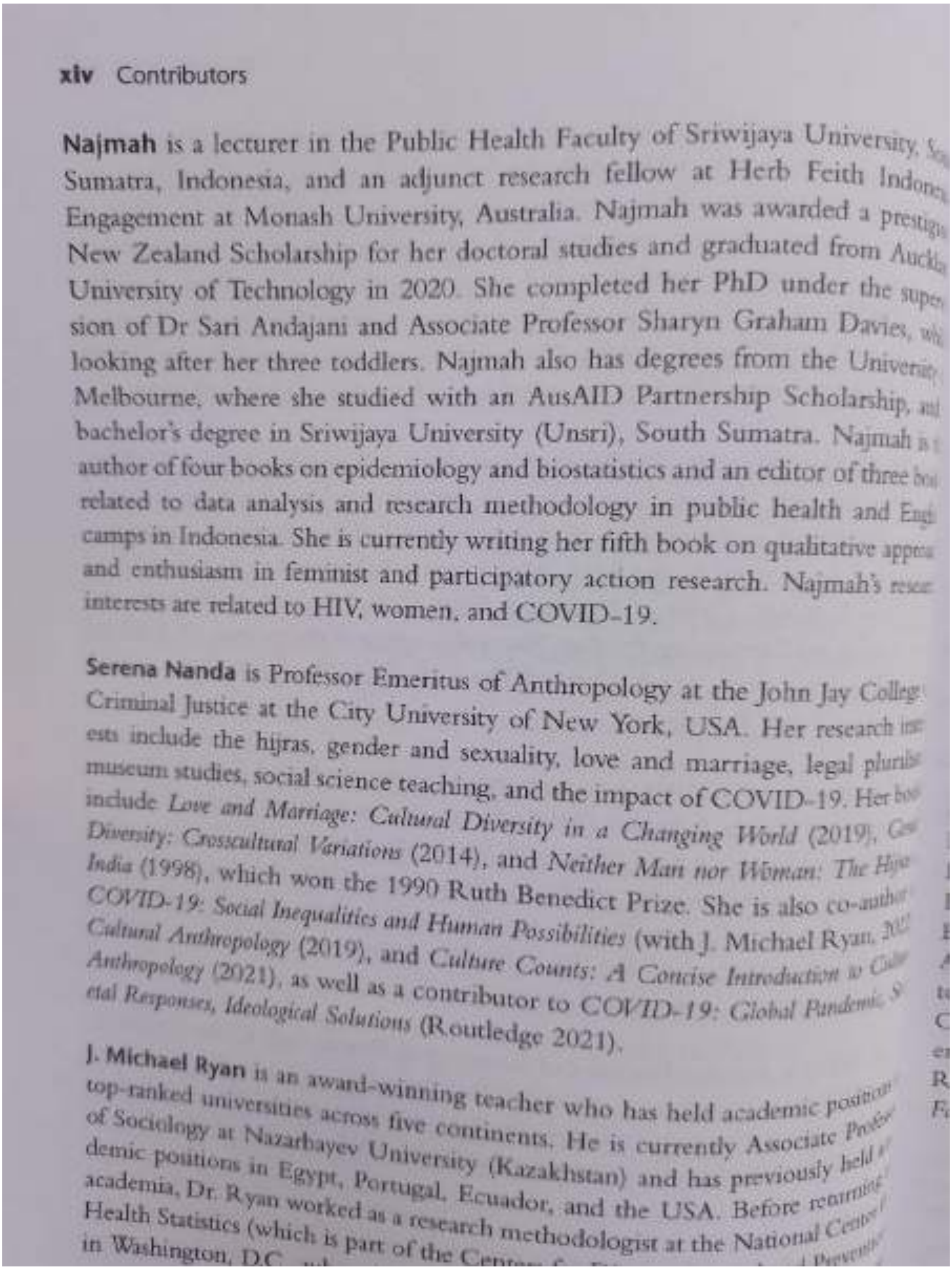
Experiences of Health Workers in the COVID-19 Pandemic
In Their Own Words
Edited by Marie Bismark, Karen Willis, Sophie Lewis and Natasha



CONTENTS

[Daftar Isi]

FIGUR

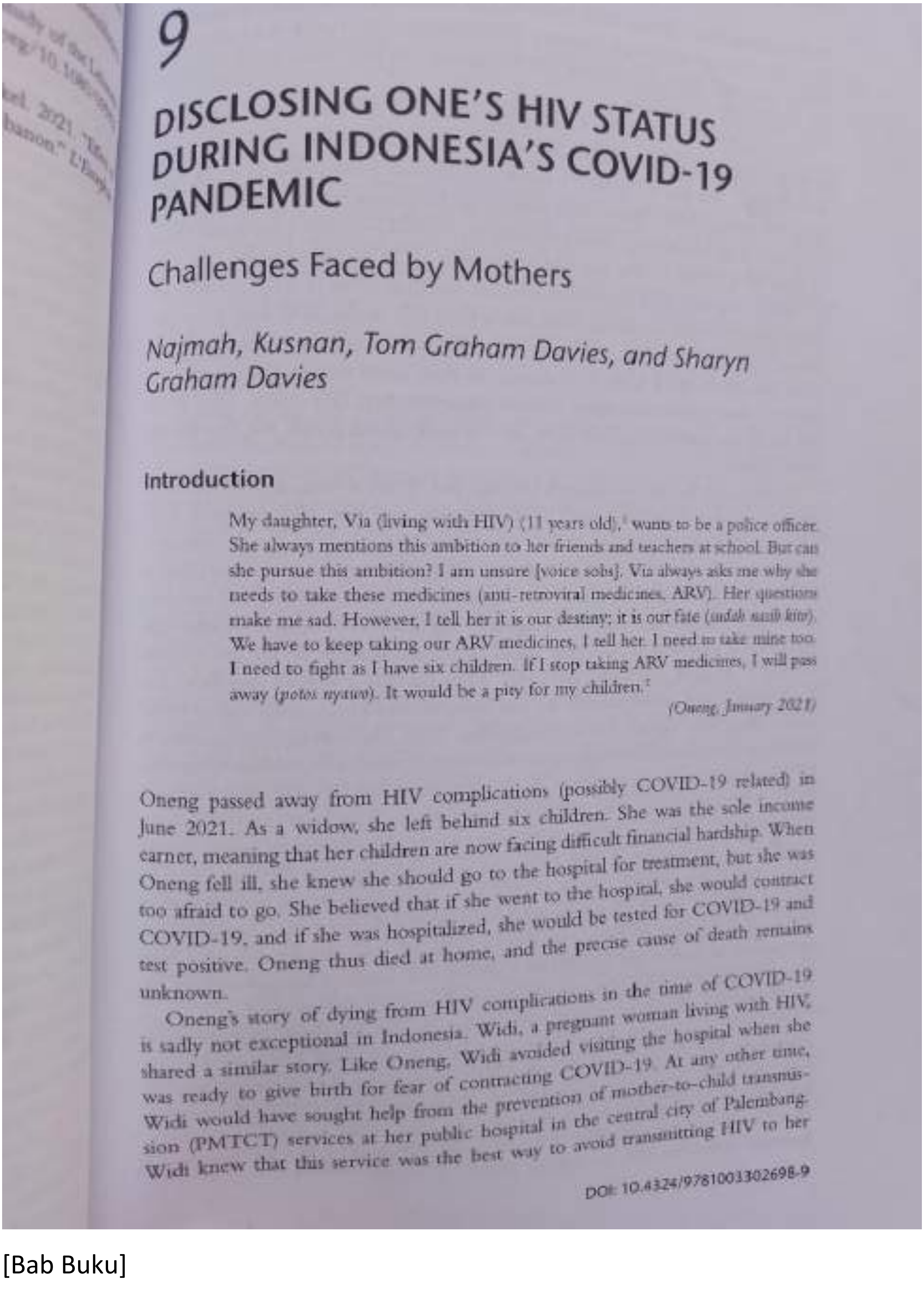


Najmah is a lecturer in the Public Health Faculty of Sriwijaya University, S
Sumatra, Indonesia, and an adjunct research fellow at Herb Feith Indone
Engagement at Monash University, Australia. Najmah was awarded a prestigi
New Zealand Scholarship for her doctoral studies and graduated from Auckla
University of Technology in 2020. She completed her PhD under the super
sion of Dr Sari Andajani and Associate Professor Sharyn Graham Davies, wh
looking after her three toddlers. Najmah also has degrees from the Universit
Melbourne, where she studied with an AusAID Partnership Scholarship, a
bachelor's degree in Sriwijaya University (Unsri), South Sumatra. Najmah is t
author of four books on epidemiology and biostatistics and an editor of three boo
related to data analysis and research methodology in public health and Engl
camps in Indonesia. She is currently writing her fifth book on qualitative appro
and enthusiasm in feminist and participatory action research. Najmah's resea
interests are related to HIV, women, and COVID-19.

Serena Nanda is Professor Emeritus of Anthropology at the John Jay Colleg
Criminal Justice at the City University of New York, USA. Her research inte
ests include the hijras, gender and sexuality, love and marriage, legal plurali
museum studies, social science teaching, and the impact of COVID-19. Her boo
include *Love and Marriage: Cultural Diversity in a Changing World* (2019), *Ge
Diversity: Crosscultural Variations (2014), and *Neither Man nor Woman: The Hij
India (1998), which won the 1990 Ruth Benedict Prize. She is also co-autho
COVID-19: Social Inequalities and Human Possibilities (with J. Michael Ryan, 20
Cultural Anthropology (2019), and *Culture Counts: A Concise Introduction to Cu
Anthropology (2021), as well as a contributor to *COVID-19: Global Pandemic, S
etal Responses, Ideological Solutions (Routledge 2021).

J. Michael Ryan is an award-winning teacher who has held academic positio
top-ranked universities across five continents. He is currently Associate Profe
of Sociology at Nazarbayev University (Kazakhstan) and has previously held
demic positions in Egypt, Portugal, Ecuador, and the USA. Before returning
academia, Dr. Ryan worked as a research methodologist at the National Cente
Health Statistics (which is part of the Cent
in Washington, D.C.

[Profil Penulis]



9

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

Challenges Faced by Mothers

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

Introduction

> My daughter, Via (living with HIV) (11 years old),[1] wants to be a police officer. She always mentions this ambition to her friends and teachers at school. But can she pursue this ambition? I am unsure [voice sobs]. Via always asks me why she needs to take these medicines (anti-retroviral medicines, ARV). Her questions make me sad. However, I tell her it is our destiny; it is our fate (*sudah nasib kita*). 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 nyawa*). It would be a pity for my children.[2]
>
> *(Oneng, January 2021)*

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

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

DOI: 10.4324/9781003302698-9

[Bab Buku]

unborn baby. Like Oneng, Widi believed that hospitals had the highest number of COVID-19 patients in South Sumatra. Widi thus gave birth to her baby at her village hospital, and while she felt able to disclose her HIV status, the hospital did not offer PMTCT services.

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

Parallels may be drawn between Oneng's and Widi's stories, as both highlight the cultural silence surrounding HIV in Indonesia and how HIV intersects with COVID-19. Both HIV and COVID-19 are veiled by a culture of denial, with governments, and even health officials, downplaying their respective dangers ([illegible] and Ryan 2023). Sadly, this silence has resulted in increased suffering and preventable deaths. There is also a gendered aspect to this silence. For instance, mainstream narratives in Indonesia declare that "good" wives and mothers do not get infected with HIV. As such, disclosing one's HIV status classifies a woman ipso facto as a "bad" woman (e.g., someone who has had high-risk sexual intercourse and/or intravenous drug use) (Najmah, Davies, and Andajani 2020). This classification exacerbates the already difficult health and economic challenges experienced by women living with HIV. As such, some women "choose" to stay silent about their HIV status when they try to access pregnancy care. The culture of silence also feeds into and exacerbates fears of COVID-19, which are then compounded by the ill-treatment by health service providers of women living with HIV. The women living with HIV we came to know during this research told us of their lives. Sadly, their stories include a great deal of suffering and of economic struggle to meet daily necessities, as well as the stigma of living with HIV, in a time of COVID-19. This chapter examines how inequalities in gender and health care intersect with a lack of support services for women living with HIV that exclude women from the help they need.

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

Research Setting and Method

Our research site is located in Palembang, South Sumatra, Indonesia. Palembang is bordered by the Banyuasin Regency to the north, east, and west and Muara Enim and Ogan Ilir Regency to the south. Palembang's area is 40,000 km², with a population of 1.7 million people in 2020 (Badan Pusat Statistik 2020). Palembang is divided into two main areas by the Musi River: Seberang Ilir and Seberang Ulu. The average monthly income of a Palembang worker is approximately Rp 1.2 million ($85 US in 2022), with about 200,000 or 11 percent of the population living on less than half of that, Rp 480,000 (about $35 US per month, in April 2022) (CEIC 2019). While men and women over 15 years have similar access to education, unpaid domestic work in the home is still largely undertaken by women, with about 92 percent of women doing the majority of domestic work (Miranda 2011), a high rate by OECD (Organisation for Economic Co-operation and Development) standards.[7]

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

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

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

A Snapshot of HIV in Indonesia

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

The availability of anti-retroviral treatment is low, with only about 2[illegible] percent of people living with HIV (PLHIV) able to access it (UN AIDS 2020). There [illegible] considerable stigma and condemnation of sex outside marriage, resulting in higher rates of STD transmission (Wibawa 2019), including HIV. Same-sex relationships are generally met with public disapproval in Indonesia, meaning that LGBTQ[illegible] people face significant public and law-based discrimination, with gay clubs and [illegible] health center frequently raided by police (Human Rights Watch 2018; [illegible] 2015). Similarly, people living with HIV are more likely to experience [illegible] directed at them and have higher rates of suicide and other mental health [illegible] (Breuer et al. 2011; Sherr et al. 2011). There is some positive news. Due to [illegible] efforts to combat HIV, the reported number of new cases of HIV has declined from 38,000 in 2015 to about 28,000 in 2020 in Indonesia (UN AIDS 2020).

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

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

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

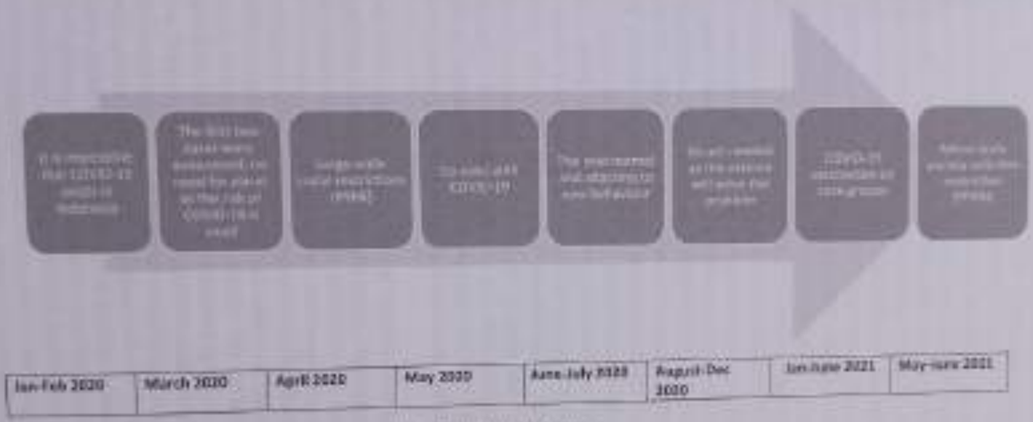


FIGURE 9.1 Timeline of government responses to the COVID-19 pandemic

The Indonesian government's initial response to the COVID-19 pandemic [illegible] a lost opportunity to successfully reduce the impact of this deadly disease, [illegible]larly in light of its impacts on women living with HIV. Statements made [illegible] Indonesian government initially denied the possibility that COVID-19 [illegible] at all in Indonesia. Following the first confirmed cases, the government's [illegible] then changed from denying the existence of the disease to downplaying [illegible] case's lethality. Controversy surrounded the government with statements [illegible] ministers and legislative members alike vigorously understating the virus's [illegible] impact. For example, in February 2020, the minister of transportation, [illegible] stated, "Indonesian people are immune to Corona because we like to eat '[illegible]ing' [a small portion of rice with anchovy, egg, fried fermented soya bean [illegible] and other ingredients wrapped in banana leaves]" (Redaksi 2020). Ironically, [illegible] then exposed to COVID-19 and treated twice for the virus (Sitorus 2020).

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

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

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

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

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

Similarly, during the Eid[4] celebration, the Islamic day that takes place at the end of the holy month of Ramadhan, an inconsistent and highly telling statement was made by Indonesian president Joko Widodo. Despite social distancing and physical movement restrictions, he encouraged the Indonesian people to do "*pulang kampong*", meaning to break physical distancing restrictions and visit their hometowns during the long holiday. Similarly, the minister of tourism and creative economy, Sandiaga Uno, undermined his government's own goals of restricting movement by reopening popular tourism destinations such as Bali, and another minister allowed the entry of Chinese health workers into Indonesia (Najmah, Davies, and Kusnan 2021).

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

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

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

> And right now, I feel sick because of increasing stomach acid. I was [illegible] in an emergency room in a public hospital. Health workers provided [illegible] treatment, therefore I was motivated to recover. Health workers knew I [illegible] living with HIV, and I had to undergo some procedures, including [illegible] in the emergency room. Then, during my hospitalization, I underwent [illegible] ultrasound checks. So many doctors cared for me, and I believe [illegible] 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 [illegible])*

Women living with HIV in this study shared with us the struggle to get HIV care. HIV service provision decreased during the pandemic, as medical [illegible] were stretched. The already present alienation felt by women subject to HIV-related stigma was worsened by COVID-19 protocols such as physical distancing between patients living with HIV and doctors. In some instances, tables were used as barriers to minimize contact between HIV-positive women and health workers at VCT because of COVID-19 concerns. Before the pandemic, women living with HIV would normally consult doctors without any separation and would [illegible] counselling room. Interestingly, physical separation was not carried out by doctors who had been well trained for HIV programs (Najmah observation during HIV fieldwork, 2017–2018). However, physical distancing became the norm during the pandemic (Romania 2023). With the shortage of health workers, well-trained HIV doctors who normally provided HIV therapy had to double up their roles as general practitioners treating COVID-19. Consequently, the limited access to HIV-related health specialists compounded the reluctance of women living with HIV to get health care, even when they were feeling extremely sick. Oneng spoke of her experience:

> The doctor who has a role in HIV treatment also has another role as [illegible]ing COVID-19. Therefore, he was overworked and not able to give [illegible] help or provide consultation. There was no chest check or other direct physical check-ups. The doctor only listened to our symptoms and then [illegible] my drug. That was all. When my mouth was full of scurvy, the doctor suggested gargling with water and salt, and there was no other suggestion [illegible] what medicine I should take or other suggestions. I was disappointed [illegible] asked myself why I visited the HIV facilities. I sit at a distance of 1.5 [illegible]

> regular check-ups for my child. I think it is better not to consult about my health condition, rather than my heart is broken.
>
> *(Oneng, a virtual interview)*

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

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

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

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

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

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

The Triple Bind of COVID-19 Restrictions

COVID-19 restrictions were performed as strategies to reduce the spread of COVID-19. Initially, the government restricted travel between regions. In addition, due to shortages of health workers, hospitals restricted health services to minimize COVID-19 transmission. Finally, social restrictions led to avoiding hospital visits due to misinformation (Ryan 2023) about COVID-19 testing or COVID misdiagnoses. Unfortunately, the triple bind of COVID-19 restrictions created a missed opportunity to prevent HIV transmission among mothers and children, as many mothers living with HIV may not disclose their HIV status to [illegible] get the proper care.

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

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

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

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

> I was initially hesitant to have my child (during pandemic) because I was afraid that I might transmit HIV to my baby. I also had fears of COVID-19 and travel restrictions from my village to Palembang. You know the pandemic is a difficult time for us (including economic challenges). There is an 80% chance[6] that my child would be infected with HIV. However, my husband supports me in treating our baby together if our baby gets HIV.
> (Widi, virtual interview

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

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

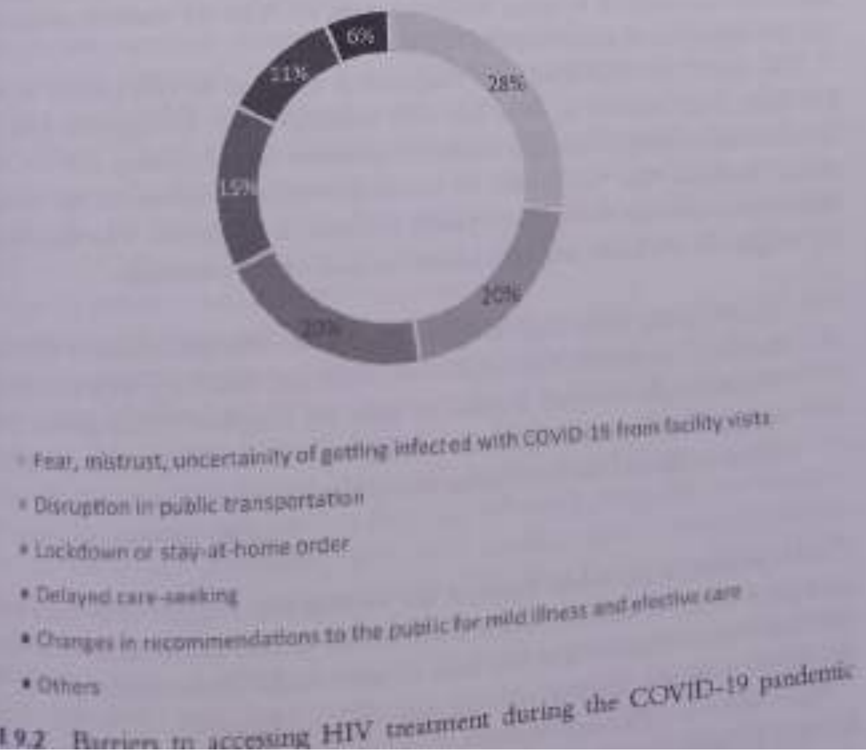


FIGURE 9.2 Barriers to accessing HIV treatment during the COVID-19 pandemic

> of me, inject the medicine for me. In my observation, health workers are more afraid of HIV compared to COVID-19.
>
> (*Nika, an informal interview; read Nika's story in Inside Indonesia; Najmah, Davies, and Kusnan 2021*)

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

The disruption to HIV prevention services during the COVID-19 pandemic, including HIV screening for pregnant women, means more mothers are at a higher risk of not knowing their HIV status and more babies are at risk of potentially becoming infected with HIV (Global Fund 2020; Jiang, Zhou, and Weiming 2020). However, the silence surrounding HIV in healthcare settings means midwives and obstetricians often do not talk about HIV to pregnant patients. Consequently, not all midwives and obstetricians recommend that pregnant women do an HIV test, thus reinforcing the stigma (Hopkyns and van den Hoven 2023; Mondal 2023). As a result, many women may know their HIV status only after their children suffer from opportunistic infections, including malnutrition, and were offered an HIV test in the late stage in hospital. Unfortunately, COVID-19 restrictions also affect the late diagnoses of their children's HIV status.

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

> The attending nurse explained that the doctor who specialized in treating my daughter's condition had other work to do and could not treat my daughter. Therefore, the hospital decided to refer my daughter to the public hospital at 10 pm. After arriving in the emergency room in the public hospital, the doctor explained the HIV status of my daughter (in a low tone of voice).
>
> (*Nur, an informal interview, 2020*)

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

Nur's child is a moving example of

not offered an HIV test at any time from 2017 to 2020. After experiencing three miscarriages, Nur was offered a complete blood test, which cost her Rp 3,000,000 (about US $210 in 2022), but the test did not include HIV screening.

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

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

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

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

The notion of shame is a key aspect of Indonesian and Muslim culture. Muslim women are in general taught to have a sense of shame, and being modest and shy is a part of the Muslim faith (*iman*). In this study, unfortunately, shame prevented many of our respondents from disclosing their HIV status and accessing health services and led to psychological difficulties. At the individual level, women living with HIV in Indonesian society may feel ashamed, dirty, and not respected or needed, and at the community level, HIV is often seen as something people contract as punishment for acting immorally (DeWees and Miller 2023). Therefore, silence is one means to avoid feeling the shame of being exposed to negative public attitudes, or silence is deployed when accessing much-needed health services, particularly with the constraints imposed on health workers during the COVID-19 pandemic where they may not have the resources to help PLHIV. Interestingly, staying silent may be interpreted as acceptance of the unfairness of health services (Wong-Padoongpat and Barrie 2023) and as a form of destiny or *takdir*, thus undermining public demand for improvements in treating HIV.

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

Unprofessional attitudes can happen in healthcare settings due to non-transparent communication between the patient and health workers (Griffiths, Alhassan, and Perera 2023). This lack of transparency is exacerbated by the inability of some health workers to separate the moral values that underpin their perspective about women living with HIV and the necessity to act professionally in carrying out their work. In an emergency situation, such as the COVID-19 pandemic, maintaining health services for these marginalized groups does not occur. Therefore, the COVID-19 pandemic may result in organizational silence or systematic silence that can be a threat to patients' health, as seen in previous health crises in the past (Henriksen and Dayton 2006).

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

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

Unfortunately, the national health system is not protecting patients' rights to care, particularly during the COVID-19 pandemic.

Conclusion

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

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

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, Anandita Eka Putri, Riska Isnaini, S.Gz, Erni Wahyuni, Sita Nariswari, and dr Chynta Rahma Vanvie. Also thank you for the research grant from Alumni Grant Scheme Round 2, Australian Awards for Indonesia, 2020–2021. Thank you Monash University and Sriwijaya University for supporting this research.

Notes

1 All names used in this research are pseudonyms.

2 Yo jadi itu yang bikin aku sedikit, apo ye (Terisak). Sedikit bingung cak itu nah. Apo yo [illegible] cak itu nah. Sampe sekarang pun dio kadang, ngapolah adek nih minum obat terus mak ye katonyo. Iyo kadang itu yang bikin, yo sedikit terenyuh kan. Jadi yo aku kalo sudah garisan kito, sudah garis nasib kito. Yo diterimo bae lah dulu. Yo cak mano jalan Tuhan kagek. InsyaAllah pasti ado jalan kan. Cak itu. Di sekolah disuruh namo, terus cita-cita, hobi kan, cak itu kan. Idak. Alhamdulillah, idak. Kalo menang yang itu nah

aku. Yo aku fokusken lah dulu, kagek lebeh parah. Aku punyo anak 6 look ... juanglee galo ini. Kalo potos, atau potos pulok nyawo kasian merek

3 More information can be found here: Miranda, V. (2011). "Cooking, Caring and Volunteering: Unpaid Work Around the World." OECD Social, Employment and Migration Working Papers, No. 116, OECD Publishing. doi: 10.1787/5kghrjm8s142-en

4 Eid ul-Fitr, also called Hari Raya Puasa or Hari Raya Aidilfitri in Southeast Asia, is the first day of Shawwal in Islamic calendar. It is celebrated as Lebaran in Indonesia. It refers to a process of spiritual rebirth or becoming pious again.

5 Yo dio kan sekarang lagi sibuk jugo ngorus pandemi. Jadi kalo kito, agak ini ... dan tuh agak cak mano ye agak kurang, kurang terlalu detail cak itunah ... nah, jauh dio ngobati kito tuh jauh. Idak do istilahnyo kayak, diperiksa dado, ... apo, idak. Denger ladahan kito, yosudah agek kito ganti obat. Cak itu bae. Jadi ... raso kecewa, jadi sy sudahlah buat apo curhat dengan dokter ini kato aku. ... senep bae kan istilahnyo cuma. Itupun kemaren, suruh mangap (buka mulut) ... setiawan. Terus kito nanya baek-baek, minum ini bae, kumur-kumur ... Cak itu. Oleh ukelah kato aku. Jadi dak katek istilah masokan yang lain ... kan ibaratnyo. Obat nah yang bagus yang ini bu, minum ini, minum ini. Idak ... Iyooon, jaraknyo pake, sudah dio dibalik meja, mungkin sekitar semeter ... gah lah kito dodok sekarang. Hampir seluruh sih. Tapi kalo yang di bagian ... ibaratnyo idak do terlalu cak mano sih. Dak tau ngapo. Kalo di bagian anak-anak, ... dooe bejarak. Mereka tetep perikso, perikso dado, perikso apo, perikso ini, idak ... pada aku saket ati lagi, kupikir kan talak ke lah samo lah.

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

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

Bibliography

AHF (AIDS Healthcare Foundation) Indonesia. 2016. "Indonesia." https://www.aidshealth.org/global/Indonesia/.

Anugerah, Pijar. 2021. "Covid: Mengapa Masih Ada Orang Yang Menyangkal Pandemi Maut Itu?" www.bbc.com/indonesia/majalah-58035319.

Badan Pusat Statistik. 2020. *Kota Palembang Dalam Angka Palembang Municipality in Figures*. Jakarta: BPS-Statistics Indonesia.

Basavaraju, Anuradha. 2021. "Toxoplasmosis in HIV Infection: An Overview." *Tropical Parasitology* 6, no. 2.

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

Bennett, Linda. 2016. "Sexual Morality and the Silencing of Sexual Health Within Indonesian Infertility Care." In *Sex and Sexualities in Contemporary Indonesia*, edited by Linda Bennett and Sharyn Graham Davies, 148–66. London: Routledge.

Breslin, Eileen T. 2023. "Schooling during Lockdown: Experiences, Legacies and Implications." In *Pandemic Pedagogies: Teaching and Learning during the COVID-19 Pandemic*, edited by J. Michael Ryan, 73–95. London: Routledge.

Breuer, Erica, Landon Myer, Helen Struthers, and John A. Joska. 2011. "HIV/AIDS and

Butt, Leslie. 2011. "Can You Keep a Secret? Pretences of Confidentiality in HIV/AIDS Counseling and Treatment in Eastern Indonesia." *Medical Anthropology* 30, no. 3: 319–38.

CEIC. 2019. "Indonesia Average Household Income: Palembang Municipality." Jakarta. https://www.ceicdata.com/en/indonesia/cost-of-living-survey-shh2018-average-monthly-household-income-by-cities/average-household-income-palembang-municipality-other.

Chenneville, Tiffany, Kemesha Gabbidon, Patricia Hanson, and Cashea 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, no. 12.

Chookajorn, Thanat, Theerarat Kochakarn, Chaiwat Wilasang, Namfon Kotanan, and Charin Modchang. 2021. "Southeast Asia is an Emerging Hotspot for COVID-19." *Nature Medicine*, no. 27: 1495–96.

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

Dale, Sannisha K., Mardge H. Cohen, Gwendolyn A. Kelso, Ruth C. Cruise, Kathleen M. Weber, Cheryl Watson, Jane K. Burke-Miller, and Leslie R. Brody. 2014. "Resilience among Women with HIV: Impact of Silencing the Self and Socioeconomic Factors." *Sex Roles*, no. 70: 221–31.

DeWees, Mari A., and Amy C. Miller. 2023. "Managing COVID-19 (and Gender): An Analysis of US News Coverage on Reported Menstrual Disruptions and Vaccines." In *COVID-19: Surviving a Pandemic*, edited by J. Michael Ryan, 120–33. London: Routledge.

Gafar, Alfian, Dewi Elizadiani Suza, Ferry Efendi, Eka Mishbahatul Mar'ah Has, Ahmad Putra Pramono, and Ika Adelia Susanti. 2020. "Determinants of Contraceptive Use among Married Women in Indonesia." *F1000 Research* 9: 193.

Global Fund. 2020. *The Impact of COVID-19 on HIV, TB and Malaria Services and Systems for Health*. Geneva: Global Health Campus.

Griffiths, Merlyn A., Pia A. Albinsson, and B. Yasanthi Perera. 2023. "Balancing Rights with Responsibilities: Citizens' Responses to Expert Systems COVID-19 Infodemics." In *COVID-19: Individual Rights and Community Responsibilities*, edited by J. Michael Ryan, 28–53. London: Routledge.

Ha, Pham Nguyen, Nguyen Thi Kim Chuc, Ho Thi Hien, Mattias Larsson, and Anastasia Pharris. 2013. "HIV-Related Stigma: Impact on Healthcare Workers in Vietnam." *Global Public Health* 8 (Suppl): S61–S74.

Henriksen, Kerm, and Elizabeth Dayton. 2006. "Organizational Silence and Hidden Threats to Patient Safety." *Health Services Research* 41, no. 4: 1539–54.

Hopkyns, Sarah, and Melanie van den Hoven. 2023. "Linguistic Access, Belonging, and Symbolic Power during the COVID-19 Pandemic." In *COVID-19: Cultural Change and Institutional Adaptations*, edited by J. Michael Ryan, 77–95. London: Routledge.

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.

Jiang, Hongbo, Yi Zhou, and Tang Weiming. 2020. "Maintaining HIV Care during the COVID-19 Pandemic." *The Lancet* 7 (5):e308–e309.

Knight, Kyle, and Julia Bleckner. 2023. "No Magic Bullets: Lessons from the COVID-19 Pandemic for the Future of Health and Human Rights." In *COVID-19: Individual Rights and Community Responsibilities*, edited by J. Michael Ryan, 185–200. London: Routledge.

Kompas. 2021. "Ini Perbedaan Aturan PPKM Level 1, 2, 3 dan 4 Level 3" 9. https://

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

Mbanya, Dora, Jerome Ateudjieu, Claude Tayou Tagny, Sylvie Moudourou, Marcel Monny Lobe, and Lazare Kaptue. 2010. "Risk Factors for Transmission of HIV in a Hospital Environment of Yaounde, Cameroon." *International Journal of Environmental Research and Public Health* 7, no. 5: 2085–100.

Ministry of Health. 2013. *National Action Plan of Prevention of Mother to Child Transmission (PMTCT) Program 2013–2017*. Jakarta, Indonesia: Ministry of Health Indonesia.

——— 2018. *Report of Situation Analysis of HIV/AIDS in 2017*. Jakarta, Indonesia: The Indonesian Ministry of Health.

Mondal, Srsti. 2023. "COVID-19 and the Contagion of Social Stigma: Evidence from India." In *COVID-19: Cultural Change and Institutional Adaptations*, edited by J. Michael Ryan, 129–46. London: Routledge.

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: Auckland University of Technology.

Najmah, Sari Andajani, and Sharyn Graham Davies. 2020. "Perceptions of and Barriers to HIV Testing of Women in Indonesia." *Sexual and Reproductive Health Matters* 28, no. 2

Najmah, Sharyn Graham Davies, and Sari Andajani. 2020. "Wives and Mothers and HIV" https://www.insideindonesia.org/wives-and-mothers-and-hiv.

Najmah, Sharyn Graham Davies, and Kusnan. 2021a. "What Is Behind Vaccine Hesitancy in Indonesia?" www.newmandala.org/whats-behind-covid-19-vaccine-hesitancy-in-indonesia.

——— 2021b. "Endless Stigma of HIV and COVID-19." *Inside Indonesia*, May 11, 20 https://www.insideindonesia.org/endless-stigma-of-hiv-and-covid-19.

Najmah, Sari Andajan Kusnan, Sharyn Graham Davies, and Tom Graham Davies. 2021. "COVID-19 Denial in Indonesia." www.insideindonesia.org/covid-19-denial-in-indonesia.

Nanda, Serena, and J. Michael Ryan. 2023. "The Importance of Culture in Understanding the COVID-19 Pandemic." In *COVID-19: Cultural Change and Institutional Adaptations*, edited by J. Michael Ryan, 29–44. London: Routledge.

Public Health Office of Palembang. 2021. *Situation Analysis of HIV in Palembang*. Palembang, Indonesia: Public Health Office of Palembang.

Putra, Gusti Ngurah Edi, Desri Astuti, Dyah Anantalia Widyastari, and Dusita Phuengsamran. 2018. "Prevalence and Determinants of Condom Use among Male Adolescents in Indonesia." *International Journal of Adolescent Medicine and Health* 33 (November 2

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

Romania, Vincenzo. 2023. "COVID-19 and the Transformations of the Interaction Order: Patternization and De-Ritualization of Social Interactions." In *COVID-19: Cultural Change and Institutional Adaptations*, edited by J. Michael Ryan, 45–57. London: Routledge.

Ryan, J. Michael. 2023. "COVID-19: Cultural Changes, and Institutional Adaptations." In *COVID-19: Cultural Change and Institutional Adaptations*, edited by J. Michael Ryan, 1–. London: Routledge.

Sanford, Adam G., Stacy L. Smith, and Dinur Blum. 2023. "Going Viral: How Social Media Increased the Spread of COVID-19 Misinformation." In *COVID-19: Individual Rights and Community Responsibilities*, edited by J. Michael Ryan, 54–76. London: Routledge.

Schultz, Nikolaj. 2023. "Did the Pandemic Teach Us Something New about Class? COVID-19 as an Experiment in 'Geosocial Class' Interests." In *COVID-19: Cultural Change and Institutional Adaptations*, edited by J. Michael Ryan, 58–76. London: Routledge.

Sherr, Lorraine, Claudine Clucas, Richard Harding, Elissa Sibley, and Jose Catalan. 2011. "HIV and Depression – A Systematic Review of Interventions." *Psychology, Health & Medicine* 16, no. 5: 494–527.

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

UN AIDS. 2020. "Indonesia." https://www.unaids.org/en/regionscountries/countries/indonesia. Geneva: UN AIDS.

USAID. 2021. "Health." https://www.usaid.gov/indonesia/health. New York: US AID.

Volmink, Jimmy, and Ben Marais. 2008. "HIV: Mother-to-child Transmission." *BMJ Clinical Evidence*, February 5. Accessed April 26, 2022.

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

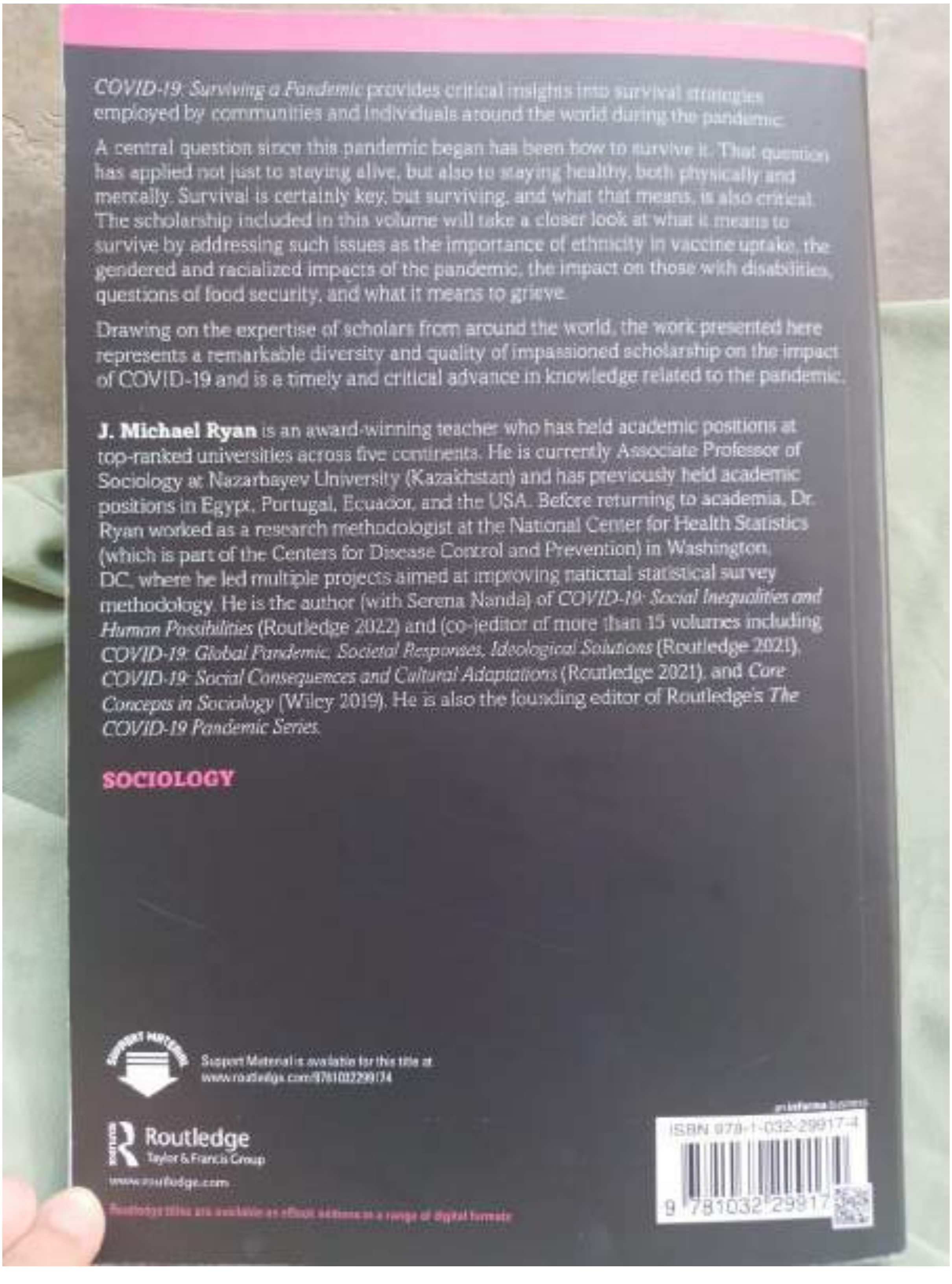
Wong-Padoongpat, Gloria, and Aldo Barrita. 2023. "The Fast and Slow Violence of the COVID-19 Pandemic on Asians in the USA." In *COVID-19: Cultural Change and Institutional Adaptations*, edited by J. Michael Ryan, 147–58. London: Routledge.

World Health Organization. 2015. "WHO Validates Elimination of Mother-to-child Transmission of HIV and Syphilis in Cuba." Accessed April 26, 2022. https://www.who.int/news/item/30-06-2015-who-validates-elimination-of-mother-to-child-transmission-of-hiv-and-syphilis-in-cuba.

Wulandari, Luh Putu Lila, Dinar S. M. Lubis, Putu Widarini, Desak Nyoman Widyanthini, I Made Ady Wirawan, and Dewa Nyoman Wirawan. 2019. "HIV Testing Uptake among Pregnant Women Who Attending Private Midwife Clinics: Challenges of Scaling up Universal HIV Testing at the Private Sectors in Indonesia." *The International Journal of Health Planning and Management* 34, no. 4: 1399–407.

Wyżgowski, Przemysław, Anna Rosiek, Tomasz Grzela, and Krzysztof Leksowski. 2016. "Occupational HIV Risk for Health Care Workers: Risk Factor and the Risk of Infection in the Course of Professional Activities." *Therapeutics and Clinical Risk Management*, 989–94.

Yulius, Hendri. 2015. *Same-Sex Marriage in Indonesia*. Melbourne: The University of Melbourne.



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

A central question since this pandemic began has been how to survive it. That question has applied not just to staying alive, but also to staying healthy, both physically and mentally. Survival is certainly key, but surviving, and what that means, is also critical. The scholarship included in this volume will take a closer look at what it means to survive by addressing such issues as the importance of ethnicity in vaccine uptake, the gendered and racialized impacts of the pandemic, the impact on those with disabilities, questions of food security, and what it means to grieve.

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

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

SOCIOLOGY

Support Material is available for this title at
www.routledge.com/9781032299174

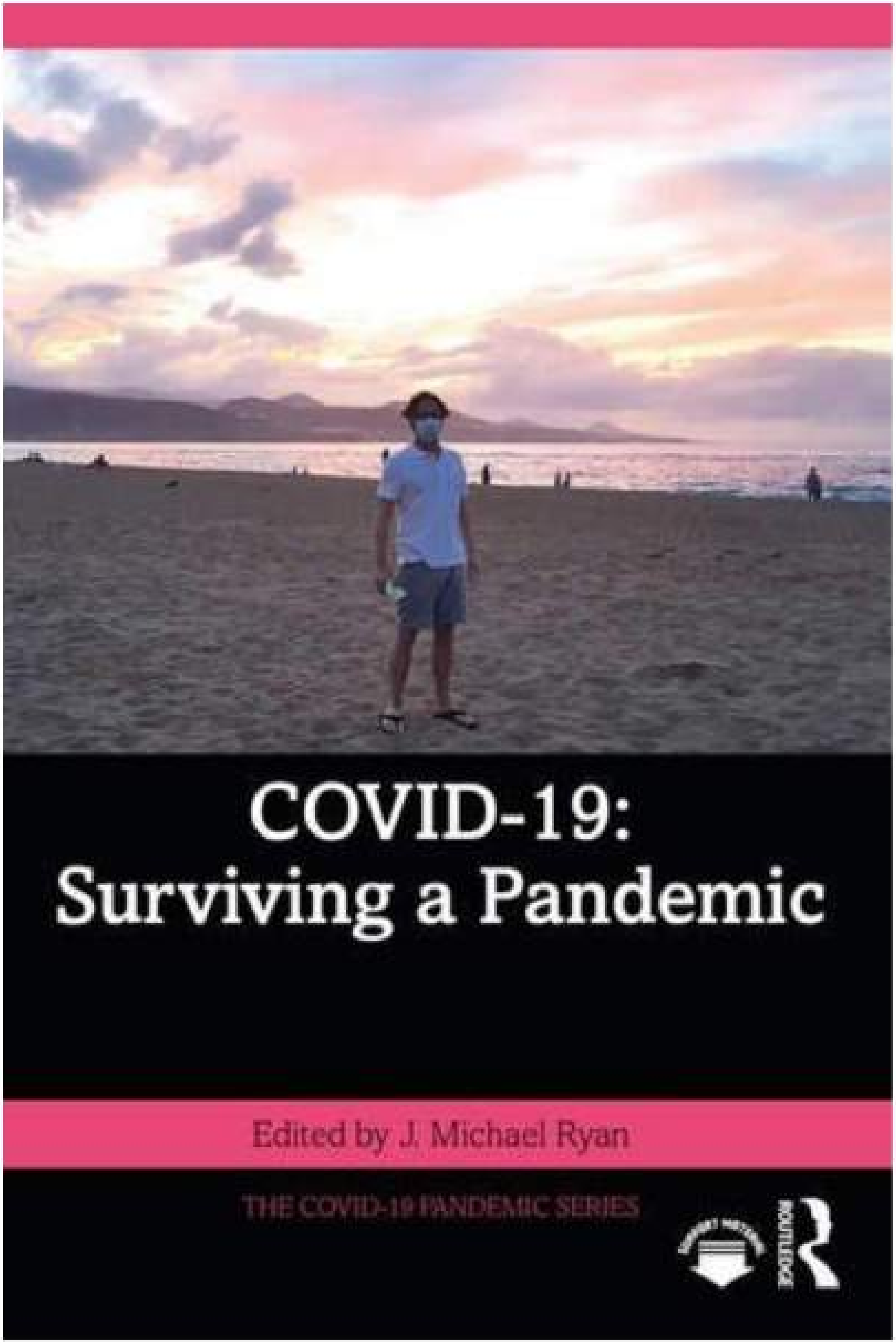
Routledge
Taylor & Francis Group
www.routledge.com

an informa business
ISBN 978-1-032-29917-4

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

by Najmah Najmah

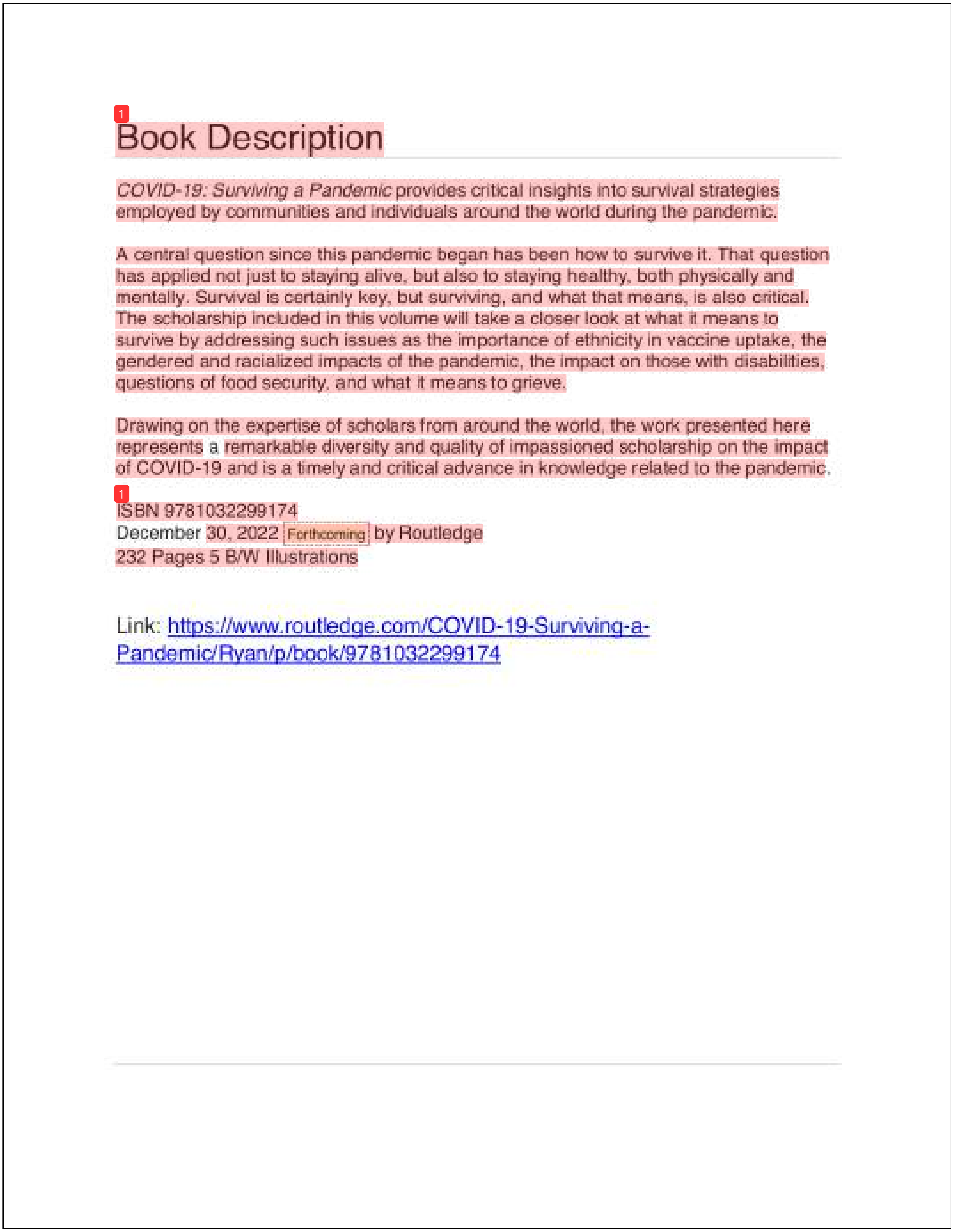
Submission date: 24-Dec-2022 03:56AM (UTC+0700)
Submission ID: 1986269479
File name: Najmah_Routledge_2022.pdf (689K)
Word count: 9112
Character count: 49412



COVID-19:
Surviving a Pandemic

Edited by J. Michael Ryan

THE COVID-19 PANDEMIC SERIES



Book Description

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

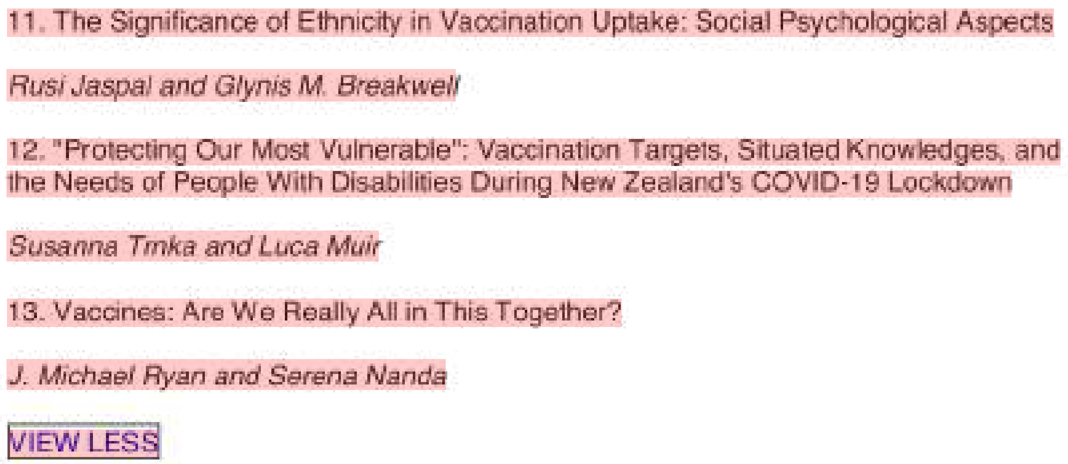
A central question since this pandemic began has been how to survive it. That question has applied not just to staying alive, but also to staying healthy, both physically and mentally. Survival is certainly key, but surviving, and what that means, is also critical. The scholarship included in this volume will take a closer look at what it means to survive by addressing such issues as the importance of ethnicity in vaccine uptake, the gendered and racialized impacts of the pandemic, the impact on those with disabilities, questions of food security, and what it means to grieve.

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

ISBN 9781032299174
December 30, 2022 Forthcoming by Routledge
232 Pages 5 B/W Illustrations

Link: https://www.routledge.com/COVID-19-Surviving-a-Pandemic/Ryan/p/book/9781032299174

Table of Contents



11. The Significance of Ethnicity in Vaccination Uptake: Social Psychological Aspects

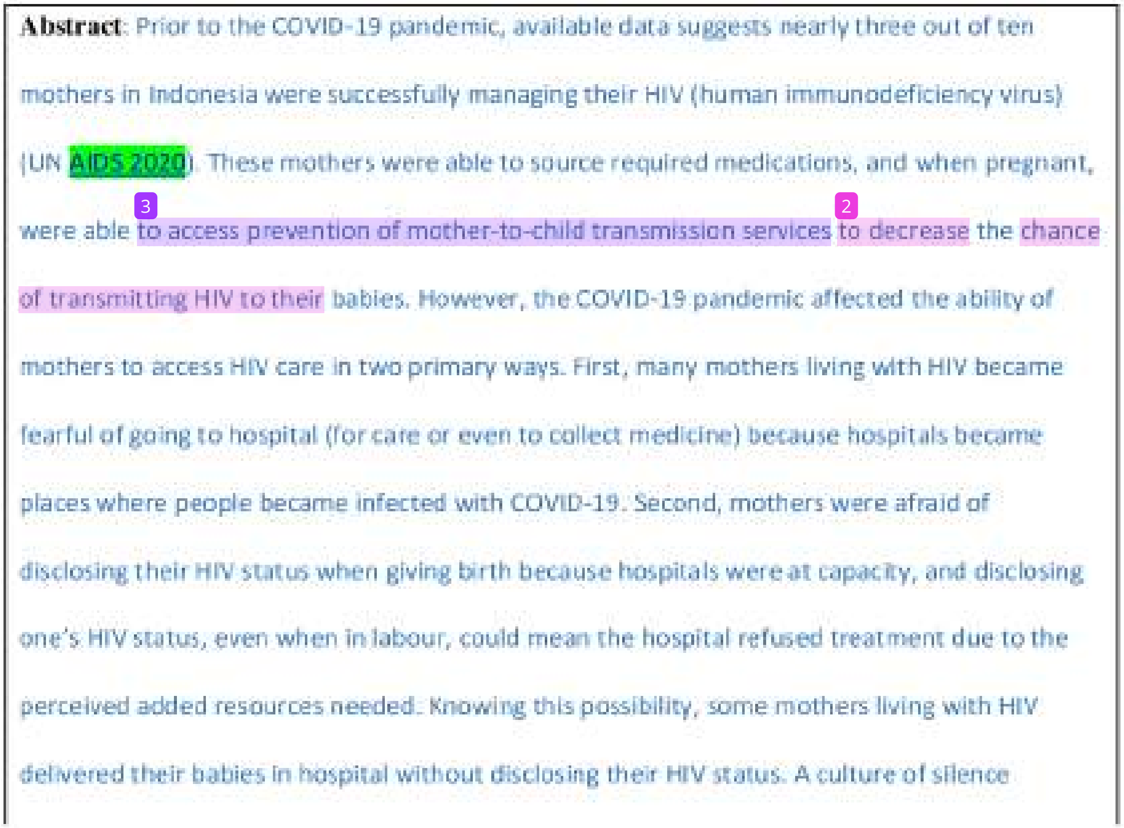
Rusi Jaspal and Glynis M. Breakwell

12. "Protecting Our Most Vulnerable": Vaccination Targets, Situated Knowledges, and the Needs of People With Disabilities During New Zealand's COVID-19 Lockdown

Susanna Trnka and Luca Muir

13. Vaccines: Are We Really All in This Together?

J. Michael Ryan and Serena Nanda



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

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

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

9

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

Challenges Faced by Mothers

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

Introduction

> My daughter, Via (living with HIV) (11 years old),[i] wants to be a police officer. She always mentions this ambition to her friends and teachers at school. But can she pursue this ambition? I am unsure [voice sobs]. Via always asks me why she needs to take these medicines (anti-retroviral medicines, ARV). Her questions make me sad. However, I tell her it is our destiny; it is our fate (sudah nasib kito). We have to keep taking our ARV medicines, I tell her. I need to take mine too. I need to fight as I have six children. If I stop taking ARV medicines, I will pass away (potos nyawo). It would be a pity for my children.[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 difficult financial hardship. When Oneng fell ill, she knew she should go to the hospital for treatment, but she was too afraid to go. She believed that if she went to the hospital, she would contract COVID-19, and if she was hospitalized, she would be tested for COVID-19 and test positive. Oneng thus died at home, and the precise cause of death remains unknown.

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

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

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

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

Research Setting and Method

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

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

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

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

A Snapshot of HIV in Indonesia

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

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

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

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

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

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

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

The Indonesian government's initial response to the COVID-19 pandemic was a lost opportunity to successfully reduce the impact of this deadly disease, particularly in light of its impacts on women living with HIV. Statements made by the Indonesian government initially denied the possibility that COVID-19 could exist at all in Indonesia. Following the first confirmed cases, the government's narrative then changed from denying the existence of the disease to downplaying the disease's lethality. Controversy surrounded the government with statements made by ministers and legislative members alike vigorously understating the virus's potential impact. For example, in February 2020, the minister of transportation, Budi Karya, stated, "Indonesian people are immune to Corona because we like to eat 'nasi kucing' [a small portion of rice with anchovy, egg, fried fermented soya bean (tempeh), and other ingredients wrapped in banana leaves]" (Redaksi 2020). Ironically, he was then exposed to COVID-19 and treated twice for the virus (Sitorus 2020).

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

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

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

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

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

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

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

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

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

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

Women living with HIV in this study shared with us the struggle to get HIV care. HIV service provision decreased during the pandemic, as medical resources were stretched. The already present alienation felt by women subject to HIV-related stigma was worsened by COVID-19 protocols such as physical distancing between patients living with HIV and doctors. In some instances, tables were used as barriers to minimize contact between HIV-positive women and health workers in VCT because of COVID-19 concerns. Before the pandemic, women living with HIV would normally consult doctors without any separation and would sit closely in a counselling room. Interestingly, physical separation was not carried out by doctors who had been well trained for HIV programs (Najmah observation during PhD fieldwork, 2017–2018). However, physical distancing became the norm during the pandemic (Romania 2022). With the shortage of health workers, well-trained HIV doctors who normally provided HIV therapy had to double up their roles as general practitioners treating COVID-19. Consequently, the limited access to HIV-related health specialists compounded the reluctance of women living with HIV to get health care, even when they were feeling extremely sick. Oneng spoke of her experiences.

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

(Oneng, a virtual interview)[v]

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

(Eda in a focus group discussion)

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

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

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

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

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

The Triple Bind of COVID-19 Restrictions

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

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

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

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

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

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

(Widi, virtual interview)

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

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

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

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

[Insert 15032-5591 - 009-Figure-002 Here]

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

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

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

> The attending nurse explained that the doctor who specialized in treating my daughter's condition had other work to do and could not treat my daughter. Therefore, the hospital decided to refer my daughter to the public hospital at 10 pm. After arriving in the emergency room in the public hospital, the doctor explained the HIV status of my daughter (in a low tone of voice).vii
>
> (Nur, an informal interview, 2020)

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

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

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

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

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

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

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

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

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

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

Another example of silence is seen in Widi's story. Widi also decided not to disclose her HIV status because if she tried to access care, she feared she might have been denied the opportunity to deliver her baby in the hospital. The hospital also did not carry out the mandatory HIV test, which should have been part of regular blood testing before her delivery. Widi was placed in a no-win situation, just like every woman living with HIV. Disclosing may lead to a negative response such as receiving demeaning health services, but if they do not disclose, their health will worsen and they risk further complications or even death. In this way, purposeful silencing by mothers living with HIV during the COVID-19 pandemic may be interpreted as a protest against the hopelessness experienced by women when accessing health services. First, the government failed to provide health services for these marginalized groups before and during the pandemic. Second, there is institutionalized discrimination in health settings, therefore health workers often have an unprofessional attitude towards patients living with HIV (Butt 2011; Najmah et al. 2020). Third, women living with HIV may assume the perceived barriers as a destiny given to them by God (takdir). In other words, they feel they do not deserve proper care and they must accept this as a way to reduce their sins in the hereafter (akhirat). Sadly, silencing may be associated with lower resilience of mothers living with HIV in surviving life with HIV (Dale et al. 2014). Unfortunately, the national health system is not protecting patients' rights to care, particularly during the COVID-19 pandemic.

Conclusion

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

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

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, Anandita Eka Putri, Riska Isnaini, S.Gz, Erni Wahyuni, Sita Nariswari and dr Chynta Rahma Varvie. Also thank you for the research grant from Alumni Grant Scheme Round 2, Australian Awards for Indonesia, 2020–2021. Thank you Monash University and Sriwijaya University for supporting this research.

Notes

Bibliography

AHF (AIDS Healthcare Foundation) Indonesia. 2016. "Indonesia." https://www.aidshealth.org/global/indonesia/.

Anugerah, Pijar. 2021. "Covid: Mengapa Masih Ada Orang Yang Menyangkal Pandemi Maut Itu?" www.bbc.com/indonesia/majalah-58035319.

Badan Pusat Statistik. 2020. Kota Palembang Dalam Angka Palembang Municipality in Figures. Jakarta: BPS-Statistics Indonesia.

Basavaraju, Anuradha. 2021. "Toxoplasmosis in HIV Infection: An Overview." Tropical Parasitology 6 (2).

BBC News. 2021. "Delta Variant: Which Asian Countries are Seeing Rising Cases?" www.bbc.com/news/world-asia-53420537.

Bennett, Linda. 2016. "Sexual Morality and the Silencing of Sexual Health Within Indonesian Infertility Care." In Sex and Sexualities in Contemporary Indonesia, Linda Bennett and Sharyn Graham Davies (eds.), 148–166. London, UK: Routledge.

Breslin, T. 2022. "Schooling during Lockdown: Experiences, Legacies and Implications." In Pandemic Pedagogies: Teaching and Learning during the COVID-19 Pandemic, J. Michael Ryan (ed.). London: Routledge.

Breuer, E., L. Meyer, H. Struthers, and J. A. Josca. 2011. "HIV/AIDS and Mental Health Research in Sub-Saharan Africa: A Systematic Review." African Journal of AIDS Research 10 (2): 101–122.

Butt, L. 2011. "Can You Keep a Secret? Pretences of Confidentiality in HIV/AIDS Counseling and Treatment in Eastern Indonesia." Medical Anthropology 30 (3): 319–338.

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).

Chookajorn, T., T. Kochakarn, C. Wilasang, N. Kotanan, and C. Modchang. 2021. "Southeast Asia is an Emerging Hotspot for COVID-19." Nature Medicine (27): 1495–1496.

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

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.

Dale, S. K., M. H. Cohen, G. A. Kelso, R. C. Cruise, K. M. Weber, C. Watson, and L. R. Brody. 2014. "Resilience among Women with HIV: Impact of Silencing the Self and Socioeconomic Factors." Sex Roles (70): 221–231.

DeWees, M., and A. Miller. 2022. "Managing COVID-19 (and Gender): An Analysis of U.S. News Coverage on Reported Menstrual Disruptions and Vaccines." In COVID-19: Surviving a Pandemic, J. Michael Ryan (ed.). London: Routledge.

Gafar A, Suza DE, Efendi F, Has EMM, Pramono AP, Susanti IA. 2020 "Determinants of contraceptive use among married women in Indonesia." F1000 research, 9:193 London UK.

Global Fund. 2020. The Impact of COVID-19 on HIV, TB and Malaria Services and Systems for Health. Geneva: Global Health Campus

Griffiths, M., P. Albinsson, and B. Perera. 2022. "Balancing Rights with Responsibilities: Citizens' Responses to Expert Systems COVID-19 Infodemics." In COVID-19: Rights and Responsibilities, J. Michael Ryan (ed.). London: Routledge.

Ha, P. N., N. T. Chuc, H. T. Hien, M. Larsson, and A. Pharris. 2013. "HIV-Related Stigma: Impact on Healthcare Workers in Vietnam." Global Public Health 8 (Suppl): S61–S74.

Henriksen, K., and E. Dayton. 2006. "Organizational Silence and Hidden Threats to Patient Safety." Health Services Research 41 (4): 1539–1554.

Hopkyns, S., and M. van den Hoven. 2022. "Linguistic Access, Belonging, and Symbolic Power during the COVID-19 Pandemic." In COVID-19: Cultural and Institutional Changes and Challenges, J. Michael Ryan (ed.). London: Routledge.

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.

Jiang, Hongbo, Y Zhou, and Tang Weiming. 2020. "Maintaining HIV Care during the COVID-19 Pandemic." The Lancet 7 (5):e308–e309.

Knight, K., and J. Bleckner. 2022. "No Magic Bullets: Lessons from the COVID-19 Pandemic for the Future of Health and Human Rights." In COVID-19: Rights and Responsibilities, J. Michael Ryan (ed.). London: Routledge.

Kompas. 2021. "Ini Perbedaan Aturan PPKM Level 1, 2, 3 dan 4 Level 3." 9. https://www.kompas.com/tren/read/2021/07/31/150000165/ini-perbedaan-aturan-ppkm-level-1-2-3-dan-4

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

Mbanya, D., J. Ateudjieu, C. T. Tagny, S. Moudourou, M. M. Lobe, and L. Kaptue. 2010. "Risk Factors for Transmission of HIV in a Hospital Environment of Yaounde, Cameroon." International Journal of Environmental Research and Public Health 7 (5): 2085–2100.

Ministry of Health. 2013. National Action Plan of Prevention of Mother to Child Transmission (PMTCT) Program 2013–2017. Jakarta, Indonesia: Ministry of Health Indonesia.

Ministry of Health. 2018. Report of Situation Analysis of HIVAIDS in 2017. Jakarta, Indonesia: The Indonesian Ministry of Health.

Mondal, S. 2022. "COVID-19 and the Contagion of Social Stigma: Evidence from India." In COVID-19: Cultural and Institutional Changes and Challenges, J. Michael Ryan (ed.). London: Routledge.

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: Auckland University of Technology.

Najmah, Sari Andajani, and Sharyn Graham Davies. 2020. "Perceptions of and Barriers to HIV Testing of Women in Indonesia." Sexual and Reproductive Health Matters 28 (2).

Najmah, S. G. Davies, and S. Andajan. 2020. "Wives and Mothers and HIV." https://www.insideindonesia.org/wives-and-mothers-and-hiv

Najmah, Kusnan, Sari Andajan, Sharyn Graham Davies, and Tom Graham Davies. 2021. "COVID-19 Denial in Indonesia." www.insideindonesia.org/covid-19-denial-in-indonesia.

Najmah, Sharyn, Graham Davies, and Kusnan. 2021. "What Is Behind Vaccine Hesitancy in Indonesia?" www.newmandala.org/whats-behind-covid-19-vaccine-hesitancy-in-indonesia.

Najmah, Sharyn Graham Davies, and Kusnan. 2021. "Endless stigma of HIV and COVID-19" Inside Indonesia, May 31, 2021. https://www.insideindonesia.org/endless-stigma-of-hiv-and-covid-19.Nanda, S., and J. Ryan. 2022. "The Importance of Culture in Understanding the COVID-19 Pandemic." In COVID-19: Cultural and Institutional Changes and Challenges, J. Michael Ryan (ed.). London: Routledge.

Public Health Office of Palembang, 2021. Situation Analysis of HIV in Palembang. Palembang, Indonesia:Public Health Office of Palembang.

Putra, Igne, D. Astuti, D. A. Widyastari, and D. Phuengsamran. 2018. "Prevalence and Determinants of Condom Use Among Male Adolescents in Indonesia." International Journal of Adolescent Medicine and Health 33 (November 29).

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

Romania, V. 2022. "COVID-19 and Transformations of the Interaction Order: Erosion, Patternization, and De-ritualization of Social Interactions." In COVID-19: Cultural and Institutional Changes and Challenges, J. Michael Ryan (ed.). London: Routledge.

Ryan, Michael. 2022. "Cultural Changes and Institutional Adaptations." In COVID-19: Cultural and Institutional Changes and Challenges, J. Michael Ryan (ed.). London: Routledge.

Sanford, A., S. Smith, and D. Blum. 2022. "Going Viral: How Social Media Increased the Spread of COVID-19 Misinformation." In COVID-19: Rights and Responsibilities, Michael Ryan (ed.). London: Routledge.

Schultz, N. 2022. "Did the Pandemic Teach Us Something New about Class? COVID-19 as an Experiment in 'Geo-Social Class' Interests." In COVID-19: Cultural and Institutional Changes and Challenges, J. Michael Ryan (ed.). London: Routledge.

Sherr, L., C. Clucas, R. Harding, E. Sibley, and J. Catalan. 2011. "HIV and Depression – A Systematic Review of Interventions." Psychology, Health & Medicine 16 (5): 494–527.

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

UN AIDS. 2020. Indonesia. " https://www.unaids.org/en/regionscountries/countries/indonesia. UN AIDS, Geneva.

USAID. 2021. Health. https://www.usaid.gov/indonesia/health. New York: US AID.

Volmink, J. A., and B. Marais. 2008. "HIV: Mother-to-child Transmission." BMJ Clinical Evidence, February 5. Accessed April 26, 2022.

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

Wong-Padoongpat, G., and A. Barrita. 2022. "The Fast and Slow Violence of the COVID-19 Pandemic on Asians in the USA." In COVID-19: Cultural and Institutional Changes and Challenges, J. Michael Ryan (ed.). London: Routledge.

World Health Organization. 2015. "WHO Validates Elimination of Mother-to-child Transmission of HIV and Syphilis in Cuba." Accessed April 26, 2022. https://www.who.int/news/item/30-06-2015-who-validates-elimination-of-mother-to-child-transmission-of-hiv-and-syphilis-in-cuba

Wulandari, L. P. L., D. S. Lubis, P. Widarini, D. N. Widyanthini, I. M. A. Wirawan, and D. N. Wirawan. 2019. "HIV Testing Uptake among Pregnant Women Who Attending Private Midwife Clinics: Challenges of Scaling up Universal HIV Testing at the Private Sectors in Indonesia." The International Journal of Health Planning and Management. 34 (4): 1399–1407.

Wyżgowski, P., A. Rosiek, T. Grzela, and A. Leksowski. 2016. "Occupational HIV Risk for Health Care Workers: Risk Factor and the Risk of Infection in the Course of Professional Activities." Therapeutics and Clinical Risk Management, 989–994.

Yulius, Hendri. 2015. Same-Sex Marriage in Indonesia. Melbourne: The University of Melbourne

---

[i] All names used in this research are pseudonyms.

[ii] Yo jadi itu yang bikin aku sedikit, apo ye (Terisak). Sedikit bingung cak itu nah. Apo yo biso cak itu nah. Sampe sekarang pun dio kadang, ngapolah adek nih minum obat terus mak ye katonyo. Iyo kadang itu yang bikin, yo sedikit terenyuh kan. Jadi yo aku kalo sudah garisan kito, sudah garis nasib kito. Yo diterimo bae lah dulu. Yo cak mano jalan Tuhan kagek. InsyaAllah pasti ado jalan kan. Cak itu. Di sekolah disuruh namo, teros cito-cito, hobi kan, cak itu kan. Idak. Alhamdulillah. idak Kalo memang yang itu tuh aku. Yo aku fokusken lah dulu, kagek lebeh parah. Aku punyo anak 6 ikok nak diperjuangke galo ini. Kalo potos, atau potos pulok nyawo kasian mereka.

[iii] More information can be found here: Miranda, V. (2011), "Cooking, Caring and Volunteering: Unpaid Work Around the World," OECD Social, Employment and Migration Working Papers, No. 116, OECD Publishing. doi: 10.1787/5kghrjm8s142-en.

[iv] Eid ul-Fitr, also called Hari Raya Puasa or Hari Raya Aidilfitri in Southeast Asia, is the first day of Shawwal in Islamic calendar. It is celebrated as Lebaran in Indonesia. It refers to a process of spiritual rebirth or becoming pious again.

[v] Yo dio kan sekarang lagi sibuk jugo ngorosi pandemi. Jadi kalo kito, agak ini mungkin, dio tuh agak cak mano ye agak kurang, kurang terlalu detail cak itunah ngoros cak itu nah. jauh dio ngobati kito tuh jauh. Idak do istilahnyo kayak, diperikso dado, diperikso apo, idak. Denger keluhan kito, yosudah agek kito ganti obat. Cak itu bae. Jadi aku raso kecewa, jadi ay sudahlah buat apo curhat dengan dokter ini kato aku. Kalo buat senep bae kan istilahnyo cuma. Itupun kemaren, suruh mangap (buka mulut) bae karena

---

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

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

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

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

ORIGINALITY REPORT

14%	14%	5%	0%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	www.routledge.com Internet Source	6%
2	openrepository.aut.ac.nz Internet Source	4%
3	www.ncbi.nlm.nih.gov Internet Source	2%
4	www.insideindonesia.org Internet Source	2%

Exclude quotes	On	Exclude matches	< 1%
Exclude bibliography	On		