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Sopir	Driver
Standar Pelayanan Minimal	Minimum standard in health services
Suami	Husband
Tersesat	Going astray
Tingkat kota/kabupaten	District levels
Tingkat nasional	National level
Tingkat provinsi	Provincial level
Tokoh masyarakat	Public figures
Transmisi HIV ke anak Anak	Transmit HIV to children
Undang-Undang Dasar	Constitution of the Republic of Indonesia
Wajib belajar sembilan tahun	Compulsory nine-year education
Wajib belajar duabelas tahun	Compulsory twelve-year education
Wajib ditawarkan	Must be offered
Wajib dites	Must be tested
Wali	Representatives
Wanita Idaman Lain	Another woman of a married man's dreams
Yayasan Pelita Ilmu	Lamp of Knowledge NGO
Yayasan Spiritia	Spiritia Organisation
Zina	Fornication

MSM	Men who have Sex with Men
NGO	Non-Governmental Organisation
ODHA	Orang dengan HIV-AIDS
PAR	Participatory Action Research
PCR	Polymerase Chain Reaction
<i>Pelakor</i>	<i>Perampas laki orang lain</i>
PHO	Public Health Office (Dinas Kesehatan)
PITC	Provider-Initiated Testing and Counselling
PKK	<i>Pembinaan Kesejahteraan Keluarga</i>
PLWHIV	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
<i>PNS</i>	<i>Pegawai negeri sipil</i>
<i>Posyandu</i>	<i>Pos Pelayanan Terpadu</i>
<i>Puskesmas</i>	<i>Pusat Kesehatan Masyarakat</i>
RAG	Research Advisory Group
SDGs	Sustainable Development Goals
<i>SIHA</i>	<i>Sistem Informasi HIV-AIDS</i>
SOP	Standard Operating Procedure
STI	Sexually Transmitted Infection
<i>UGM</i>	<i>Universitas Gajah Mada</i>
UNAIDS	United Nations Programme on HIV/AIDS
UNGASS	United States Assembly Special Session
UNICEF	United Nations International Children's Emergency Fund
USAID	United States Agency for International Development
<i>UUD</i>	<i>Undang-Undang Dasar</i>
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
WIL	<i>Wanita Idaman Lain</i>
WLWH	Women Living with HIV
YPI	<i>Yayasan Pelita Ilmu (Indonesian NGO)</i>

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in Indonesia and came along to support me in this journey. It is uncommon for a husband to sacrifice his job to support his wife in a dominant patriarchal society such as Indonesia, but he did it. He started his working experience in Auckland from the lowest level as a kitchen hand to better position as a head chef in a big culinary company in Auckland. He is not only a husband, a breadwinner, and a father for the kids, but also he is my discussion mate for my Ph.D. journey.

Most importantly, I would like to say thank you to the supportive environment that I received at this place, the AUT campus. AUT as a Millennial University provided a friendly environment for me, an international student and mother, to pursue my dream. When my peers asked me, “where is your Ph.D. room?” I answered, “here in the parent room or breastfeeding room”. AUT has also provided a childcare subsidy for my three kids for almost four years. What amazing support AUT has, to accommodate one-to-one meetings with learning advisors and English support, such as with Dr David Parker and Dr Quentin Allay, and Karen Margetts, the friendly liaison librarians, and Charles Grinter from AUT’s Ethics Committee helped me through the ethics process. Thus, my kids can join with me during my many meetings with AUT advisors.

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I was an ‘unsuitable’ mother...

I went back to live with my parents
I pulled myself back, found my will to live
I took antiretroviral treatment
I went back to study
I changed my lifestyle
I continued to be grateful for His blessings
My life was getting better; financially
I finished my study and got a degree

In 2016, I started to open my heart to have love again
I met him....
Would he accept me?
He did...
We learned together... worked together as a team
We also met many angels in our lives
Friendly doctors and supported nurses who care with us
Now we have our second child... he is healthy

Nothing is impossible....
I am grateful; I am not alone....
Start from ourselves and love your family....

Mona sent me this letter (via an email) after I completed my field research. The letter reflected her journey, her struggle, and life after becoming HIV-positive. FPAR facilitated an empowerment process for Mona to analyse and write about her situation and to share her story with me. Mona said to me, “Finally, I met someone to share my story that I kept secret for ages; I hope other women will learn from my story”.

Through FPAR, I have been able to retell Mona’s story and other stories told to me by HIV-positive women in my study. These mothers conveyed their painful stories, their aspirations and hopes, and solutions to the challenges faced by HIV-positive Indonesian women of reproductive age. Through my research, I learned to listen; I learned the power of sharing and collaborating with these women and how to harness trust and humility to empathise with deep feeling and real sorrow. Yet, their determination, love, and optimism amazed me.

I took the approach that assumes HIV-positive women are the real experts of their situation, and when given an appropriate and safe place to express their experiences, may be inspired through research engagement to build confidence to seek solutions that facilitate the meeting of their needs and achieving their aspirations. As a researcher, I was an instrument for reflecting

According to Muhaimin and Besral (2011), without any preventative HIV treatment among HIV-positive pregnant women in Indonesia, the government would need Rupiah (Rp) 5,300,000 (NZ\$500) for each child annually, or invest up to Rp 42 billion annually (NZ\$4,336,118) to obtain ARV treatment for 8,604 HIV-positive babies. The estimated cost of ARV treatment may be more expensive nowadays. One form of HIV care that focuses on eliminating HIV among children, is PMTCT services.

Prevention of mother-to-child of HIV transmission (PMTCT): Chances and challenges

According to the World Health Organisation (WHO), accessing PMTCT services can significantly avert the transmission of HIV from HIV-positive mothers to babies, to less than five per cent (MoH, 2013c). Without accessing PMTCT services, the risk of perinatal transmission is about 20-50% (De Cock et al., 2000). As seen in Mona's and Oneng's lived experiences, without access to any HIV care, Mona's first child was not infected with HIV, yet Oneng's last child was infected. However, after knowing her HIV status, Mona was keen to access PMTCT services when she planned to have a second child (more of Oneng's and Mona's stories are included in Chapter 5 and Chapter 7, respectively). Accessing PMTCT services can reduce the risk of HIV transmission to a child to five percent (De Cock et al., 2000).

PMTCT services in Indonesia follow a four-pronged strategy: 1) Prevention of HIV among women of childbearing age; 2) Prevention of unintended pregnancy among HIV-infected women; 3) Prevention of HIV transmission from an HIV-positive woman to her baby; and 4) Provision of appropriate treatment, care, and support to mothers living with HIV, and their children and families (MoH, 2012a, 2013d, 2015b). PMTCT generally begins during antenatal care when the woman is tested for HIV and receives the result that she is HIV positive. PMTCT also focuses on women who have been confirmed as having HIV and who plan to have more children. PMTCT services provide ARV medicines for mother and infants, safe and planned delivery, and appropriate breastfeeding practices (Hairston, Bobrow, & Pitter, 2012; Hampanda, 2012; Idele, Hayashi, Porth, Mamahit, & Mahy, 2017; Turan & Nyblade, 2013) (These four strategies are discussed further in Chapter 3).

PMTCT in Indonesia started in 1999 with projects run by an NGO in Jakarta (Imelda, 2011). The Indonesian MoH responded by preparing hospital-based PMTCT services in Indonesia

facilitator?” The common assumption of IDUs in Indonesia is that they are ‘naughty’ (Indonesian literally *nakal*) or not well-behaved people; they cannot be trusted and they may tell lies.

In 2012, I decided to conduct research related to knowledge about HIV among women of reproductive age, using secondary data from the Indonesian Demography and Health Survey (IDHS). Based on an analysis of 922 women of reproductive age, only one in ten women in South Sumatra knew that a blood test was a means of knowing HIV status. The women had poor understandings of how HIV is contracted, and not knowing VCT centres were places to undertake HIV tests, resulted in poor awareness of the potential for undertaking voluntary HIV testing (Najmah, Sari, Kumalasari, Davies, & Andajani, 2020). As noted in the story of Riko and Lasmi, I reflected that Lasmi may not have known about the risk of contracting HIV from her husband within their marriage, as he may have hidden his past experiences of being an IDU.

In 2013, I prepared my Ph.D. research protocol. My potential supervisors at that time, Sari Andajani and Sharyn Graham Davies, suggested that I discuss with local Public Health Officers about current HIV issues in my area. One officer highlighted the challenges of HIV programmes in South Sumatra and advised of the low accessing of PMTCT services. Only four HIV-positive pregnant women accessed PMTCT services in 2013, while the target was at least seven HIV-positive women a month. I also met a coordinator of the AIDS Commission in Palembang to ask about the possibility of recruiting HIV-positive women during my research fieldwork.

One year prior to commencing my Ph.D., I reflected on Riko’s story in relation to accessing PMTCT services, my initial research about poor knowledge of HIV among women of reproductive age in the general population, and my discussions with the public health officers, AIDS Commission and my proposed supervisors about low accessing of PMTCT services. I asked myself several questions: “are Indonesian women aware of their risk of contracting HIV, do women know about PMTCT of HIV, what are the barriers to accessing PMTCT services, and what do women need to enhance their access to PMTCT services?” These questions will be addressed and the answers analysed in the findings, in Chapters 5, 6, and 7. Finally, in 2014, with the guidance of my supervisors, I developed my first short research protocol on HIV-positive women’s experiences of accessing PMTCT services. I obtained my enrolment for my Ph.D. on 1st of October 2015.

Java, Borneo, Sulawesi, and Papua; see Figure 1.4), and over 17,500 small islands, of which more than 7,000 are uninhabited. Administratively, the country is divided into 34 provinces, each with its own local government, and each province is divided into regencies (*kabupaten*) and cities (*kota*).



Figure 1.4: Map of Indonesia

Note. Reprinted from *Where is Palembang in Indonesia?* by World Atlas, 2015, Quebec, Canada. Copyright (2015) by World Atlas.

Bahasa Indonesia is the official and national language of Indonesia, however, Indonesian people also speak their local dialects, of which there are more than 1,100. Indonesia officially acknowledges six religious groups: Muslims (in the majority), Catholics, Protestants, Hindus, Buddhists, and Confucianists (Bennett & Davies, 2015; The World Bank, 2018). This diversity of religion, language, geography, and culture is acknowledged in Indonesia's *Bhinneka Tunggal Ika* or Unity in Diversity (Bennett & Davies, 2015; The World Bank, 2018).

Sumatra is Indonesia's second largest island after Borneo. It is separated in the northeast from the Malay Peninsula, by the Strait of Malacca, and in the south from Java, by the Sunda Strait. The mother language for Sumatrans is Malayo-Polynesian (Austronesian) and the original inhabitants are the Malay ethnic group (*etnik Melayu*) (Encyclopaedia Britannica, 2018; Marsden, 1788). In terms of culture and religion, Sumatrans have unique characteristics with a strong Malay (*Melayu*) culture; their most common religion is Islam (Blackburn, Smith, & Syamsiyatun, 2008; Marsden, 1788; Setyawati, 2008).

Sumatra PHO (2017). Only two hospitals offered comprehensive PMTCT services for safe-delivery practice for HIV-pregnant women and prophylactic treatment for babies born to HIV-infected mothers for all regencies and cities in South Sumatra, including Palembang. Both hospitals, Moh Hoesin Hospital (public hospital) and Charitas Hospital (private hospital), were designed to provide comprehensive PMTCT services since 2007 and 2012 respectively. In Moh Hoesin Hospital, from 2008 to March 2017, of 50 pregnant women living with HIV who had accessed this service, 35 had HIV-free infants born to HIV-positive mothers, 17 babies were still on prophylaxis therapy, and only one child was confirmed as HIV positive. One mother had twins, and two mothers had used the same service in the past. In the Charitas hospital, only four HIV-positive pregnant women had ever accessed PMTCT services. The women gave birth to three HIV-negative children. Two HIV-positive mothers and two babies (twins) passed away in 2012-2017⁶.

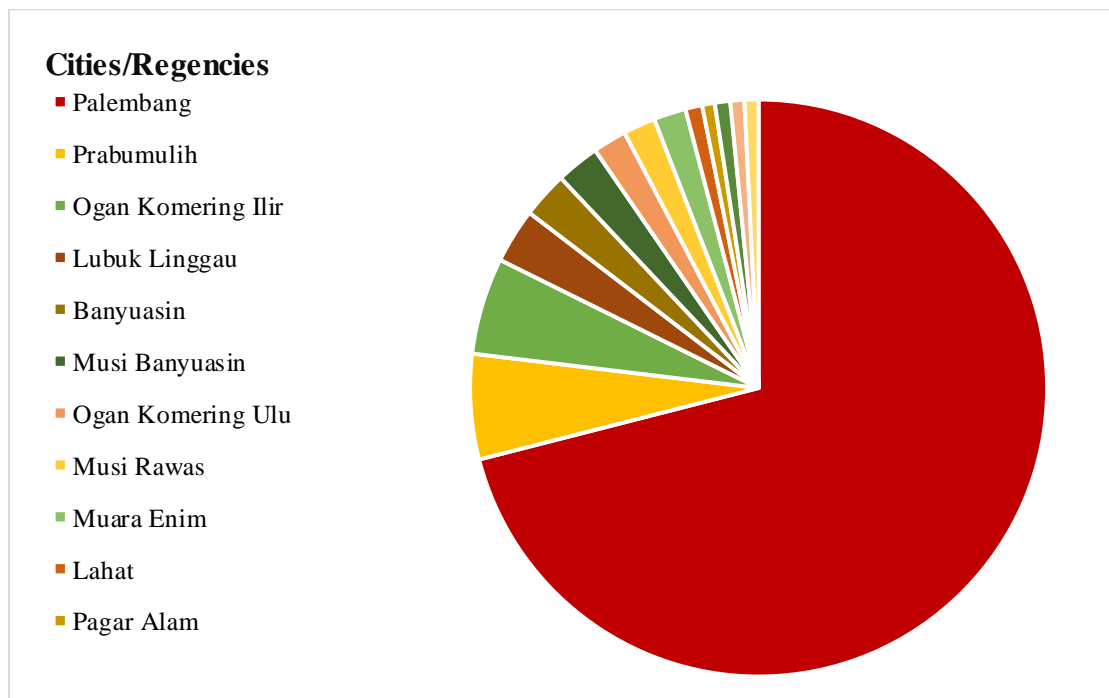


Figure 1.6: Cumulative number of HIV in 20 cities/regencies South Sumatra (1995- April 2017)

Source: South Sumatra PHO (2018)

⁶ It was challenging to get the correct data related to HIV in mothers and children; this information was given by a source who did not want to be named in this thesis.

especially relating to injecting drug use or unsafe sexual practices (i.e., having multiple sex partners or visiting sex workers). Thus, my empathy was heightened.

Being an outsider gave me some advantages. I was curious about the women's voices, ideas, and aspirations; therefore, I maintained my position as a "naïve inquirer"—a listener to learn and a learner to listen (see Bank, 1998; Merton, 1972). As an outsider, I was seen as a person who would not understand their difficult lives as HIV-positive women; therefore, they felt they needed to give me more context for my study. In addition, being an academic, a lecturer of Public Health at Sriwijaya University, and a Ph.D. student, gave me advantages in terms of gaining their trust and hopes that I would take their voices and aspirations to relevant stakeholders. For example, one of my participant's husbands even offered to be involved in my study because he was also studying at Sriwijaya University. Some HIV-positive women were adamant that their voices be delivered to the PHO (*Dinas Kesehatan*), community health centres, and hospitals because they believed I had the access, position, and networks to help. However, being an outsider, an HIV-negative woman, and well-educated, I maintained my position as a naive inquirer, as I realised that my participants were the real knowers of their problems and solutions.

In summary, being an insider and outsider offered drawbacks to generating knowledge in this study. Arguably, understanding the differences between my insider and outsider positions provided a further opportunity to reflect on the complexity of the power dynamics during data collection and analysis, particularly amongst a marginalised female population of HIV-positive women. Thus this study offers some important insights to fill gaps left by previous studies.

9. Significance of the study

This research contributes to filling the gap in current knowledge about enabling HIV-positive women to access PMTCT services in Indonesia. There are four main contributions of the present study. The first contribution is the new articulation of marital deception as a new term in the academic landscape of Indonesian sexuality studies and in work on HIV in Indonesia. The second contribution is the theoretical framework on the intersectionality lens, in order to understanding women's vulnerability to HIV in Indonesia. The third contribution is the conceptualisation of HIV-related stigma, a reflection of the two positions of HIV-positive women and health workers. The fourth contribution is using FPAR as an important

The context of women: Indonesian women's vulnerability to HIV (Chapter 2)

In this chapter, I provide an overview of HIV and women in Indonesia. Chapter 2 presents an overview of HIV and women in Indonesia. It provides a distilled overview of women positioning in Indonesian society and describes how key ideologies and norms shape their gender positioning. I elaborate on why women are vulnerable to HIV in Indonesia and key factors that shape women's vulnerability, including: low knowledge of HIV, sexual double standards, lack of condom use, fear of disclosure, stigmatisation, gender discrimination in health care settings and discrimination in policy. This chapter highlights how understanding the HIV vulnerability of Indonesian women requires understanding women's position, and the societal and religious expectations of women, in society.

Prevention of mother-to-child transmission of HIV: A global and Indonesia context (Chapter 3)

Chapter 3 provide a critical examination of PMTCT programmes globally, and then specifically in the Indonesian context. It synthesises the global response and progression of PMTCT, then moves on to discuss the history and gaps in PMTCT in Indonesia. It discusses barriers to accessing PMTCT services in Indonesia that tracks alongside the global analysis.

Methodology (Chapter 4)

Chapter 4 outlines the thinking behind my decision to use FPAR as the methodological framework for my study. This chapter contributes as an example of the FPAR framework in relation to a highly marginalised group of women to guide my research journey. It demonstrates a template for and the utility of this approach in this particular cultural and religious setting in Indonesia. It provides details of the research paradigm, pre-fieldwork preparation, field study design, participation of HIV-positive women and other participants, ethical issues and data analysis.

Findings (Chapters 5, 6, 7)

Chapter 5 through 7 present key empirical findings from the field work. The research findings are presented in three chapters. The first chapter is 'Life context of HIV-positive Indonesian women'; the second chapter is 'Barriers to accessing PMTCT services', and the final chapter is 'What women need to enhance their access to PMTCT services'.

2. Vulnerability to HIV

Vulnerability is generally defined as “the state of being left without shelter or protection against something harmful” (Merriam-Webster, 2019a, para. 1). Global studies argue that women’s vulnerability to contracting HIV from their partners or husbands is due to multiple factors, from individual to social domains, and beyond the biological domain (e.g. Baral et al., 2013; Brawner, 2014; Higgins et al., 2010; Lin et al., 2007; Ostrach & Singer, 2012). There are two common themes in global studies related to women’s vulnerability to HIV: the social cultural factors of women, particularly related to structural gender inequality and the relationship sphere, and the physiology⁷ of female reproductive systems.

The social cultural factors of women

The first contributing factor heightening women’s risk of HIV relates to structural gender inequality and the intimate sphere, such as women’s lack of social and economic power, and the different gender norms of men and women. Global studies note that women are likely to contract HIV from their sexual partners (Baral et al, 2013; Brawner, 2014; Higgins et al., 2010; Lin et al., 2007; Ostrach & Singer, 2012). Long-term monogamous relationships and marriage are considered protection against HIV and STIs when compared to other partnering patterns (e.g., serial monogamy and having multiple partners) (Adimora & Schoenbach, 2012). However, within the norm of the “universal sexual double standard”, “men’s greater access to extramarital sex” (Higgins et al., 2010, p. 436), drug use, and gendered patriarchal roles and responsibilities in a partnership, men are those more likely to contract HIV (Higgins et al., 2010; Lin et al., 2007; Ostrach & Singer, 2012). Studies about the dynamics of HIV transmission in Asia by Nguyen, Oosterhoff, Hardon, et al. (2008), Riono and Jazant (2004), and Thisyakorn (2017) provide evidence that the Asian HIV epidemic model projections are from key populations to women in the wider community through unsafe sexual practice (see Figure 2.1 and

Figure 2.2).

⁷ ‘Physiology’ is the branch of biology that deals with the normal functions of living organisms and their parts.

Indonesian Islam. For instance, many women who are not living in cities or engaged in formal work have very little influence on their lives compared to cultural and religious norms and accepted practice (*adat*). I am not discussing this topic but these authors, Linda Bennett, Lyn Parker, Julia Suryakusuma, Maria Platt, Nina Nurmila, Sari Andajani, and Sharyn Graham Davies, do.

Indonesian women and government policies

This first sub-section identifies the ways in which the roles and status of Indonesian women in domestic and public spheres are shaped by specific social and religious beliefs, particularly since Indonesian independence, and especially in the New Order (1966-1998) and the subsequent Reform era (1999-present day). This sub-section is divided into four main parts: defining gendered ideology in a patriarchal society: historical background; promoting monogamous registered marriages; restricting polygamous marriages and divorces, and regulating the roles of wives and husbands but providing more opportunities for women in the public sphere. I discuss each in turn.

Defining gender ideology in patriarchal society: Historical background

In this first sub-section, I discuss factors relating to the influence of government policies in terms of societal expectations of women in Indonesia. This gendered construction may relate to gendered ideologies that have regulated women's role and status as reflected in government policies to the present day. Initially, I define gender and gender morality, followed by a discussion of the notion of family and *Ibuism* or motherhood in the past, and its impact on societal expectations of Indonesian women in the present.

First, I discuss the definition of gender. "Gender", according to Ayubi (2019), specifically in a community with religious norms in everyday life, refers to "social behaviour related to sex that reflects religious, cultural, political, psychological and social understanding of masculinity and femininity". Gender ideology is defined as "normative beliefs about the proper roles for and fundamental natures of women and men in human societies" (Philips, 2001, p. 6016).

Historically, the notion of family (*keluarga*) has long been embedded in the everyday life of Indonesian people. Three main eras of Indonesian history are significant in relation to the importance of cultural norms of marriage and motherhood. Firstly, during the era of kingdoms (15th -17th century), then during the Dutch colonisation of Indonesia (1820-1942), and then after Indonesia become a nation in 1945. For example, William Marsden in the 17th century

women, female divorcees and widows, and single or unmarried women¹⁴. Homosexuals are also viewed as outsiders and unfitting, which may put them at risk of more discrimination, falling outside the ideal societal expectations of women.

Promoting monogamous registered marriages

In this second sub-section on Indonesian women and government regulations, I focus on UUD 1945 and the Indonesian Marriage Laws no 1 in 1974. The Indonesian governmental promotion of monogamous registered heterosexual marriage is embedded in government policies. UUD 1945 states that “everyone has right to establish a family to generate offspring through a lawful or registered marriage in a family”¹⁵. This regulation explicitly mentions that each child has the right to live, grow up, and develop, as well as the right to protection from violence or discrimination” (GoI, 1945). A man is able to marry one wife; and a wife marry with one husband¹⁶ (GoI, 1945, 1974). Registered marriage, as discussed previously, aims to protect women’s and children’s rights within the marriage registration process, and from unfair marital practices resulting in women’s vulnerability and neglected children (GoI, 1945, 1974; Nurmila, 2009, 2016).

Reflecting on my own experience, my husband and I needed to complete some procedural letters through a local religious office or KUA (*Kantor Urusan Agama*) to request a registered marriage. For example, before our marriage, we needed to complete some written forms and provide our identity cards or KTP (*Kartu Tanda Penduduk*), our family cards (*Kartu Keluarga*), and agreement forms from both families (read infoKUA, 2019). These administrative procedures are required as evidence for protecting my family’s rights (including children) in a legal system in Indonesia, such as access to public services (such as, schools,

¹⁴ In Thailand, pregnant unmarried women and sexually-active single women may be more likely to be condemned than are men. Parents may force their children to have a marriage ceremony if they know their daughter is pregnant (read Chanthasukh, 2019; Chirawatkul et al, 2012). In Malaysia, a divorcee needs to fight stigmatisation, as a ‘good’ Muslim women should not exercise her right to ask for a divorce from her husband; on the other hand, there is evidence of how challenging the life of a divorcee is, not only as a breadwinner, but also as a care-giver for children (read Pappano & Olwan, 2016)

¹⁵ see chapter XA, verse 28 B in UUD 1945

¹⁶ see Chapter I, verse 1, 2 and d 3 in UU No 1 in 1974

including the religious expectations of Muslim women. I define what is morality and gender morality, then overview the historical context of Islam in Indonesia, before discussing the values of constructed gendered morality of Muslim women in the past and present.

Morality is generally understood as matters or conducts or attitudes which are considered to be “right and wrong or good and bad” within existing social systems, taught across generations and reinforced in social norms within social relations and by social authorities (Killen & Smetana, 2013, p. 4). Gender morality, according to Ayubi (2019), a female Muslim scholar, refers to existing religious norms, embedded in social behaviours or attitudes about sex, gender status, roles and sexual relationships which are ‘correct’ or ‘acceptable’ or ‘normal’ and ‘good’, including in Muslim society.

Islam values have contributed to morality and social norms in Indonesia for many decades. Islamic traditions and teachings came to Indonesia around the 7th - 8th centuries²⁷ (Frankopan, 2018). The spread of Islam in Sumatra started after the end of the Buddhism kingdom, the Srivijaya (*Sriwijaya*) Kingdom (12th century) by Islamic traders from Middle East and India (Kuntowijoyo, 2001; Ricklefs, 2008; Vlekke, 2008). Thus, the practice of Islam in Indonesia has been part of Muslim Indonesian everyday life for many centuries²⁸. For example, Sumatrans enacted practices based on Islamic teachings, as observed by ethnographer William Marsden in the 17th century, such as circumcision, reading the Koran (*Al-Qur’an*), and enforcing the five principles or pillars of Islam: faith, prayer, charity, fasting and pilgrimage to Mecca¹ (Marsden, 1788). A well-known proverb in the Malay culture in Sumatra is “*Adat bersendi syarak, syarak bersendikan Kitabullah*” (customs are based on Sharia, and Sharia is based on the Holy Qur’an) (Setyawati, 2008, p. 72).

²⁷ In 7th and 8th century, “an unpromising start in a cave near Mecca had given birth to something like a cosmopolitan utopia (an ideal society, full of people from many countries and cultures). It marked the start of a golden age for scholars, traders, and travelers. The wealth and sophistication did not go unnoticed, those with ambition born on the edges of the Muslim world and far beyond were drawn to it like bee to honey and to seemed to those in China, South Asia and even further a field that there were possibilities that looked irresistible” (Frankopan, 2018, p. 43).

²⁸ Historically, Islam spread in two ways in Indonesia. First, by merchants of Gujarat across the Indian Ocean who were mostly from Saudi Arabia through economic systems and the marriage systems; and second, by Persians with strong features of Sufism which affiliated with natural order and mysticism (Geertz, 1976; Kuntowijoyo, 2001; Marsden, 1788; Vlekke, 2008; Woodward, 2010; Wormser, 2014).

Sexual double standards

The second societal reality of women's increased risk of HIV is the sexual double standard. However, as noted earlier, HIV infected men increase their wives' risk of HIV, as the women may not know that their male partners are infected (Higgins et al., 2010; Lin et al., 2007). This risk is similar in the Indonesian context, where the hegemony of heterosexual and monogamous marriage and double standard gender norms may also result in tensions and deceptions within or outside wedlock. Unfortunately, women may be vulnerable to contracting HIV if their husbands are HIV positive. Gender inequality within marriage, including the subordinate status of women and their lack of economic independence, impact on women's capacity to communicate and negotiate safe sex practices with their husbands, such as use of condoms (Butt, 2015; Jacobowski, 2008; Nurmila, 2016).

Lack of use of condoms and non-consented sex among married couples

The third societal reality of women that increases their vulnerability to HIV, is the lack of condom use for contraception in marriage. In relation to HIV prevention, condom use as an effective means to prevent HIV and STIs is very low amongst married couples (Pisani, 2010; Praptoraharjo et al., 2016a; Riono & Jazant, 2004). Low condom usage among married couples³⁷ may be related to access and stigmas associated with prostitution or sex outside marriage (Praptoraharjo et al., 2016b). Although effective and consistent condom use is likely to reduce the risk of contracting HIV to up to 80% (Weller & Davis-Beaty, 2002), condoms are not provided in primary health care centres such as *puskesmas*, or maternal and midwifery clinics (Praptoraharjo et al., 2016b). The challenges of condom use are worldwide, as condom use may relate to distrust, infidelity, being unloved, being less romantic, and reducing sexual pleasure (Baral et al., 2013; Higgins et al., 2010; Pisani, 2010; Randolph, Pinkerton, Bogart, Cecil, & Abramson, 2007). In addition, condom use is stigmatised as being associated with having HIV, because the practice may prevent transmission to one's partner (Baral et al., 2013; Higgins et al., 2010; Pisani, 2010; Randolph et al., 2007).

³⁷ Only 7.5 % of women (n=13,811) use non-hormonal methods such as condoms (4%) (MOH, 2013d) (NHBS, 2012). Condom use is uncommon in South Sumatra. For example, only one in two women knew that condoms could lower the risk of HIV transmission, and only one in every ten women knew that HIV infection could be detected with a blood test (Najmah et al., 2020)

UNAIDS: Start Free, Stay Free, AIDs Free

In 2016, to support WHO's four-pronged strategy, UNAIDS proposed an ambitious programme known as "Start Free Stay Free and AIDS-Free" (UNAIDS, 2017). This programme continues from the previous UNAIDS Global Plans in 2011 that prioritised 21 sub-Saharan countries for PMTCT programmes to eliminate mother-to-child HIV transmission in 2015 (UNAIDS, 2017). The progress of UNAIDS' global plan provided a promising achievement, particularly for 12 out of 21 prioritised countries with over 80% coverage of PMTCT services⁴⁴ (see Figure 1.1)

UNAIDS initiated these global plans to support the Sustainable Development Goals (SDGs), to end the AIDS epidemic by 2030, the latest global programmes replacing MDGs that ended in 2015 (see Chapter two, Introduction). UNAIDS now prioritises 23 countries with support from many international donors. The prioritised countries are 21 from sub-Sahara and two from the Asian continent, India and Indonesia (UNAIDS, 2017). The programmes⁴⁵ offer a fast-track to eliminate new HIV infections among children as well as to ensure their mothers are alive and healthy; the programmes are an ongoing process (UNAIDS, 2017). However, both key players of PMTCT programmes, WHO and UNAIDS, still tend to focus on a biomedical prevention approach, using ARV treatment with the addition of voluntary medical circumcision for HIV prevention.

Key players of PMTCT programmes

Key players are influential in the success of such programmes. There are four key players in PMTCT programmes (Table 3.2). The World Health Organization, the United Nations

⁴⁴ 21 sub-Saharan countries are: Angola, Botswana, Burundi, Cameroon, Chad, Cote d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, Uganda, United Republic of Tanzania, Zambia, and Zimbabwe.

⁴⁵ The current programmes emphasise the need to: reach and sustain HIV-positive pregnant women with HIV with lifelong HIV treatment by 2018; eliminate new HIV infections among adolescent and young women to less than 100,000 by 2020; provide voluntary medical circumcision for HIV prevention to 25 additional men by 2020 with a focus on young men aged 10-29, and provide 1.6 million children; and 1.2 million adolescents (15-19) living with HIV with ARV therapy by 2018 (UNAIDS, 2017).

integrated health information systems that have sex and age data segregated (Idele et al., 2017; UNAIDS, 2019). Arguably, these key players are also responsible for strategically advocating the global direction of PMTCT to ensure PMTCT targets to reduce HIV among children as part of global plans and the MDGs and SDGs, particularly in resource-limited countries. Thus far, I have argued that these key players may drive and implement PMTCT programmes in most of the funded countries by target-oriented programmes, including in Indonesia, the study context.

What worked and what did not work

Recent evidence suggests that increased accessibility to PMTCT services can significantly reduce mother-to-child transmission of HIV (UNAIDS, 2018; WHO 2010, 2018). For example, between 2010 and 2018, up to 1.4 million children born to HIV-positive mothers were confirmed to HIV-free. In addition, between 2016 and 2018 some middle-income countries had marked significant success in reversing mother-to-child transmission of HIV. These countries include Malaysia, Armenia, Belarus, the Republic of Moldova, Antigua, Barbuda, Bermuda, Cayman Island, Montserrat, and Saint Kitts and Nevis (UNAIDS, 2018; WHO, 2018). However, for many countries, eliminating mother-to-child HIV transmission is still challenging due to low coverage of PMTCT services.

Accessibility of PMTCT services remains poor despite global efforts to provide support. Figure 3.1: shows the global coverage of PMTCT services in 2016 and indicates that the lower the percentage of HIV-positive pregnant women who access ARV therapy, the higher rate is of perinatal HIV transmission. Countries that achieve up to 80% of PMTCT coverage will be able to reduce the rate of transmission from mothers to children to nine percent. Alternatively, the low percentage of pregnant women accessing ARV therapy indicates a high risk of mother-to-child of transmission. For example, Figure 3.1: shows that in South Asia, the risk of vertical transmission is up to 27% due to poor access to PMTCT services.

Oosterhoff, Ngoc, et al., 2008; Turan & Nyblade, 2013). Additionally, HIV-positive women may be afraid of breaches in confidentiality, such as unwanted disclosure of HIV status by accessing HIV testing or bringing home tins of formula for feeding (Busza et al., 2012; Hampanda, 2012; Hlartaithe et al., 2014). Women may face adversity such as marriage break-ups, and being ostracised by in-laws. They are likely to experience conflict between protecting their health and the health of their unborn children, or facing condemnation and blame (Gourlay et al., 2013; Hlartaithe et al., 2014; Turan & Nyblade, 2013).

The second key cultural barrier is a husband's domination of his wife's decision in regards to health care. Many women are financially dependent on their husbands who hold decision-making power. Health practices and some women require to seek permission from women's husbands for undergoing a certain test or a service plan, leading to persistent unequal ability for the wife to independently make decisions on her health, and often on the health of her children (Busza et al., 2012; Gourlay et al., 2013; Hlartaithe et al., 2014). Reviews by Busza et al. (2012) and Hlartaithe et al. (2014) in resource-poor settings found that women were generally observed to seek permission from the male head of the household or their mother in-law for decisions to access PMTCT services. In India, Vietnam, and sub-Saharan countries, women were particularly afraid of their husbands' disapproval of ante-natal HIV testing and PMTCT services, particularly women whose husband had never used any HIV related health services (Blackstone et al., 2018; Darak et al., 2012; Hlartaithe et al., 2014; Nguyen, Oosterhoff, Ngoc, et al., 2008; Panditrao et al., 2011).

3. PMTCT in Indonesia

Much has been done at a global level, yet more work is needed for better access to PMTCT services. I am focussing specifically on PMTCT in Indonesia. Indonesia is especially important because it has the lowest rate of access of PMTCT and highest rate of perinatal HIV transmission of 23 high-priority countries (21 countries in sub-Saharan Africa, and two countries in Asia-Indonesia and India) (UNAIDS, 2017). In Indonesia, only one in ten HIV-positive pregnant women access PMTCT services, and in India, one in five HIV-positive pregnant women access PMTCT services (Madhivanan et al., 2014; MoH, 2013c, 2015b; UNAIDS, 2017). The increasing number of HIV-positive children in Indonesia can be seen as a proxy factor to the low coverage and access of PMTCT services.

STIs, including HIV and AIDS [*Ikatan Perempuan Positif Indonesia* (IPPI), (2017a); MoH (2015b)].

Additional contraceptive methods are recommended for double-protection of an unintended pregnancy, such as hormonal contraception for HIV-positive women (MoH, 2015b). If the spouse chooses not to bear another child, sterilisation, either for the man or woman, may be the best option (IPPI 2017a; MoH, 2015b)⁴⁹.

Table 3.3: Recommended contraceptive methods for HIV-positive women

Contraceptive methods	HIV-positive women	
	ARV therapy	Non-ARV therapy
Non hormonal contraception		
Sterilisation (tubectomy)	V	V
Condom	V	V
Hormonal contraception		
Combination contraception pills		V
Progesterone pills		V
Progesterone implants or IUD		V
Progesterone injection method	V	

Sources: (*IPPI 2017a; MoH, 2015b*)

Note: ARV can reduce the effectiveness of some hormonal methods, so some contraceptive hormonal methods are not recommended for ARV users with the exception of progesterone injections.

Previous studies have provided evidence of family planning choices for Indonesian women, including those who are HIV-positive. However, provision of family planning by healthcare providers in Indonesia, according to Spagnoletti, Bennett, Kermode, and Wilopo (2018), is “often lacking, perpetuating misinformation, and women’s choice was not always respectful” (p. 1). For example, although men can also undertake sterilisation or a vasectomy to prevent unintended pregnancy, in Indonesia it is considered a woman’s rather than a man’s responsibility to use contraception (Amelya et al., 2016; Nurmila, 2016; Spagnoletti et al., 2018). A study in the national hospital for HIV programmes in Jakarta, Cipto Mangunkusumo Hospital, found that HIV-positive women are more likely to use long-acting contraception, such as an IUD or sterilisation, compared to women in the general population (Amelya, Andriyana, Nababan, & Gunardi, 2016). Additionally, with poorly integrated family planning,

⁴⁹ IPPI stands for *Ikatan Perempuan Positif Indonesia* or Indonesian HIV-positive women association.

have a shared responsibility, commitment, and budget to provide HIV programmes through an integrated primary health care system (Praptoraharjo et al., 2016a). Consequently, it is mandatory for each province in Indonesia and its relevant maternal and child health programmes, as well as sexual and reproductive health programmes, to implement these regulations (Praptoraharjo et al., 2016a). Achievement of PMTCT programmes by each province is evaluated regularly by the central government. Table 3.4 details the eight regulations known as the Ministry of Health Regulations (or *Peraturan Kementerian Kesehatan* or *Permenkes*) of HIV to women and children.

Table 3.4: Regulations of Ministry of Health (*Permenkes*) related to Reproductive Health and a comprehensive PMTCT service

Permenkes Number	Year	Regulation topic
21	2013	Controlling HIV and AIDs
51	2013	Guideline for the prevention of HIV transmission from mother-to-child
74	2014	Guidelines for the application of counselling and HIV tests
87	2014	Guidelines for the application of ARV therapy
97	2014	Family planning, sexual health, and maternal health services
25	2015	Implementation of laboratory tests for women who are pregnant, in labour, and after delivery in health settings and other referral services
43	2016	Minimum standards of health services (Article 12)
52	2017	Elimination of HIV, Syphilis and Hepatitis B transmission from mothers to children

Sources: (MoH, 2013a, 2013b, 2014b, 2014c, 2014d, 2015a, 2016, 2017a)

Guidelines from the MoH recommend that in all regions, with a generalised HIV epidemic⁵¹ (as in Papua), and a concentrated HIV epidemic⁵² (as in Palembang), healthcare providers must offer HIV tests to all pregnant women (MoH, 2013c, 2015b). Consequently, HIV screening should be integrated within primary health services (*Standar Pelayanan Minimal*), such as in primary health services (*puskesmas*) in each city and regency in Indonesia, consistent with the requirements of *Permenkes* no. 43, Article 12 (2016). Health workers, general practitioners,

⁵¹ ‘Generalised HIV epidemic’ refers to an epidemic in a region where HIV prevalence is over five percent in the general population, as in Papua, Indonesia

⁵² ‘Concentrated HIV epidemic’ refers to an epidemic in a region where HIV prevalence is less than one percent in the general population, but over five percent in high-risk groups

Government of Indonesia

The first sub-section of key players of PMTCT overviews primary key players within the Indonesian health system. The health reforms in Indonesia on 1st January 2014 increased universal health coverage for all Indonesians, including the provision of integrated HIV programmes within the Indonesian health system⁵³ (Mahendradhata et al., 2017; Praptoraharjo et al., 2016b). There are three main players within the Government of Indonesia (GoI): 1) National AIDS Commission (*Komisi Penanggulangan AIDS Nasional* [KPAN]); 2) MoH and PHO; and 3) BPJS (Social Insurance Administration Organisation/*Badan Penyelenggara Jaminan Sosial*). KPAN is currently disestablished, leaving the MoH and BPJS to share responsibilities of providing easy and free access to PMTCT services for HIV-positive pregnant women.

KPAN was launched in 2006 in accordance with Presidential Decree (*Perpres or Peraturan Presiden*) No. 75/2006 (GoI, 2006). KPAN was a part of the Ministry of Economic and People Prosperity, or Menkokesra (*Menteri Koordinator Bidang Ekonomi, Kesejahteraan Rakyat*). The central government encouraged regional governments to establish regional AIDS Commissions in 34 provinces and cities or municipalities to support KPAN. The main roles of KPAN were to establish strategic plans and policies for the prevention and control of HIV/AIDS, advocate regional regulations to promote HIV/AIDS, and perform regular coordination, particularly between NGO workers, key populations, and other state institutions within their regions (GoI, 2006; INAC, 2018). However, in 2016, in accordance with the Presidential Decree No. 124/2016, these were disestablished, and their functions undertaken by the Indonesian MoH at national level and the PHO at provincial and district levels (Suharni et al., 2016). Arguably, the disbanding of the KPAN was a significant change that provincial and local PMTCT programmes needed to manage, including connection with NGO and local community in district level (*kecamatan*) to promote PMTCT services (read KitaSetara, 2017; Mahendra, 2018).

The MoH and PHOs (*Dinas Kesehatan*) are the second key players within the Indonesian Government; their focus is on the health sector at national and regional levels (MoH, 2013c,

⁵³ The shift of New Order (1965-1998) to Reform Era (after 1998 till now) also impacted on the reform of bureaucracy systems in Indonesia, such as the health system, from centralisation to decentralisation to each region to maintain people's health (Mahendradhata et al., 2017).

2015b). The MoH has inter-connected roles to provide HIV prevention and treatment programmes, which include PMTCT training, and the provision of free ARV supply and HIV testing in primary health services and hospitals under PHOs in 34 provinces in Indonesia. At regional level, the PHO has been integrated as a key player responsible for performing inter-related coordination and monitoring in health institutions and other related sectors, such as NGOs and BPJS. The MoH, as the primary key player of PMTCT programmes at national level, implements centralised HIV programmes by passing regulations and guidelines. Nevertheless, there is limited community participation from provincial and municipal PHOs with the centralised MoH for the improvement of HIV programmes, shared budgeting, and coordination generally (Suharni et al., 2016).

The third key player is BPJS, the Social Insurance Administration Organisation. As noted previously, Indonesia committed to providing universal health coverage through the National Health Insurance Programme for all Indonesian people since 2014, which includes HIV-positive women. BPJS is, so far, the only insurance provider that covers treatment costs for PLWHIV, including free caesarean sections, and treatment for HIV-positive pregnant women before and after delivery (MoH, 2015c). However, women need to enrol with BPJS insurance to access free PMTCT services. All pregnant HIV-positive women are required to enrol with BPJS and make regular payments—as low as NZ\$3 a month⁵⁴ or free if registered as living in poverty—to access other medical services related to PMTCT services (Mahendradhata et al., 2017; Tangcharoensathien et al., 2011). In 2018, enrolling for social insurance was still a challenge for many poor people due to inadequate integrated data; if their poverty could not be formally verified, they were unable to qualify for free enrolment in BPJS (Mahendradhata et al., 2017). Without enrolling, HIV-positive pregnant women need to pay for some treatments relating to PMTCT services, such as caesarean sections, the main option for eliminating HIV perinatal transmission during delivery in limited resource settings with inadequate availability of CD4 and viral load testing.

In summary, MoH, PHO and BPJS are the main key players within the Indonesian health system for enhancing access to PMTCT services for WLHW. However, a lack of integration between these key players within GoI may contribute to poor implementation of PMTCT.

⁵⁴ The payment is predicted to increase as low as NZ \$11 a month in 2019 or 2020



Figure 3.4: ARUMI adventure: Searching for information about PMTCT and Family Planning for HIV-positive women (IPPI 2017a)

Note. Reprinted from *ARUMI adventure* by IPPI, 2017, Jakarta, Indonesia. Copyright (2017) by IPPI (Indonesian HIV-positive women's association).

International Donors

The third sub-section of key players in relation to PMTCT is that of international donors. There is a proliferation of international funding agencies supporting HIV programmes in Indonesia. They include the World Bank, the Australian Agency for International Development (AUSAID), the United States Agency for International Development (USAID), Partnership Funds, and The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). Together, they support the development and strengthening of HIV prevention and treatment programmes. Unfortunately however, each these international agencies has its own response to international donors (e.g. IATT, see key players at the global context), programmes, and choices of provinces to support, and some international agencies do not comply with Indonesian planning regulations (Praptoraharjo et al., 2016a). For example, AUSAID focused on high HIV prevalence provinces (Jakarta, Banten, West Java, Central Java, East Java, Bali, Papua and West Papua) for integrating of HIV programmes, harm reduction, and budgeting within Indonesian health systems, while USAID focused on community-based approach programmes

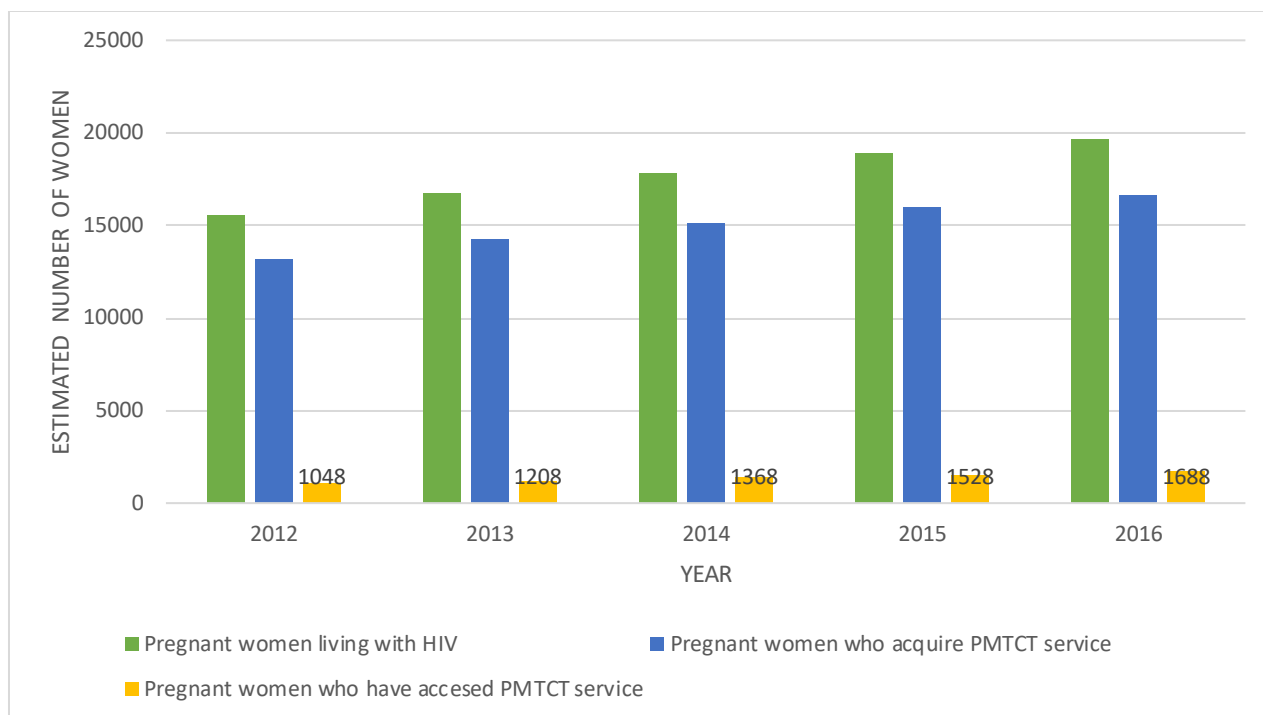


Figure 3.5: The gap between the need of PMTCT services (blue) and accessibility of PMTCT services for pregnant women living with HIV (yellow)

Source: Ministry of Health, Indonesia (2013a, 2013b)

Barriers to accessing PMTCT services in Indonesia

The increasing number of PMTCT services, and the number of pregnant women accessing antenatal HIV testing and PMTCT services are marks of success, but there are still many barriers to access. As explained earlier, globally, women may be discouraged from accessing PMTCT services for a variety of reasons, such as inadequate availability of HIV testing and ARV supply, unfair treatment by health services, poverty, and dependence on one's husband. There are also multiple fears among health workers in relation to treating HIV-positive pregnant women. The WHO identified barriers to access as the health systems, economic context, information availability, and the effects of culture, all of which are interlinked. I start with the first barrier related to health systems.

Health systems barriers

Within Indonesia, while much has been done to improve universal health access of PMTCT services, what previous researchers highlight are that there is: (1) inadequate HIV testing for pregnant women; bureaucratic processes that make accessing PMTCT services difficult; and (2) inadequate privacy for women in health settings (See health system barriers on the global context, where I explain the inadequate HIV testing and privacy in health system barriers).

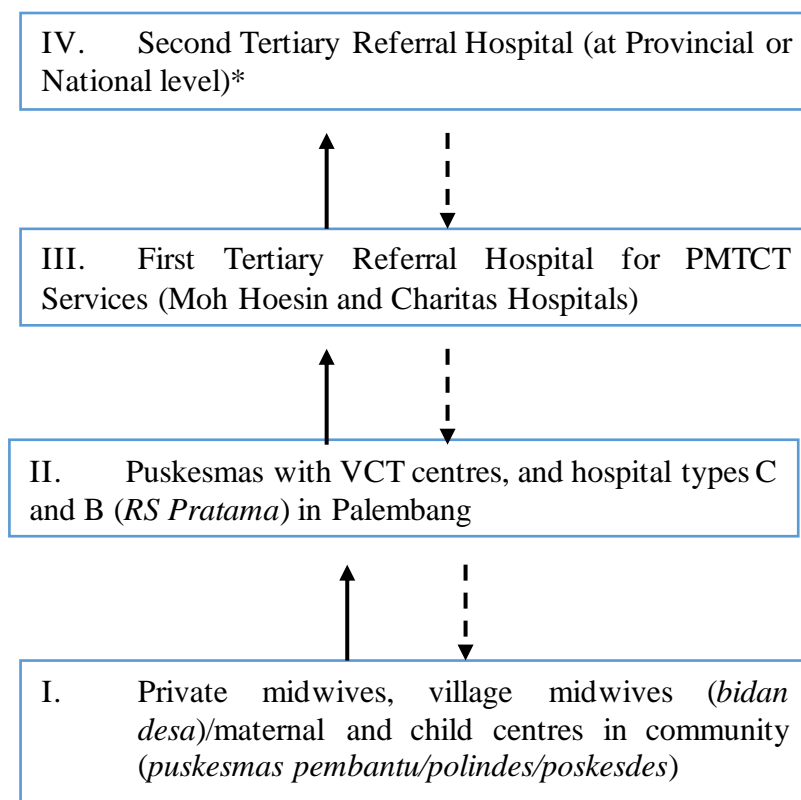


Figure 3.6: Referral system of the four pronged-strategy in PMTCT services in South Sumatra, Indonesia.

- - - - -> Referral procedure from top down
- > Referral procedure from down up to top

Source: MoH (2015)

Note. In emergency situations, HIV-positive patients may be referred directly to tertiary referral hospitals.

A third key health system barrier is that of limited space and lack of privacy for women in maternal and children health services. At *puskesmas*, or primary level in Palembang, I have observed more than one patient being admitted to an antenatal care room, which is a serious breach of the women’s privacy. At tertiary referral hospitals, women should be prepared for waits on long-waiting lists to receive services (Hidayana & Tenni, 2015; Lumbantoruan et al., 2018). Unfortunately, limited space in health settings may discourage women from accessing PMTCT services and seeking HIV testing, particularly those who decide not to disclose their

services for the prevention of transmission of HIV from mother to child in Indonesia. Within a feminist epistemology, HIV-positive women's unique views and subjectivity are central to the construction of new knowledge. Their voices and perspectives are important in raising collective critical consciousness, which can lead to social transformation. Additionally, women's empowerment within the research is critical to the work of feminist researchers (Hesse-Biber, 2012) and I, as part of this research process, learned to be aware of power and gender dynamics during the research process. The relationships between me, as the researcher, and the research participants, was also an integral part of the research process. Having discussed feminist research, the next section examines the aesthetic of empowerment within a feminist research paradigm and how it has informed my chosen methodology.

Empowerment in feminist research

The discourse on empowerment has appeared in many disciplines, such as psychology, public health, social work, and other social sciences (Carr, 2003; Gutierrez, 1990, 1995; Turner & Maschi, 2015; Wallerstein, 2006; Wang & Burris, 1994). This section highlights the importance of the empowerment process in engaging the participants so they have ownership of the research process and actively participate in order to construct knowledge related to the aims of the study. I follow the definition of empowerment by Gutierrez (1995), which is "a process of increasing personal, interpersonal, or political power so that individuals, groups, or communities can take action to improve their situation" (p. 229). Gutierrez (1990) argued that society consists of distinct groups of those who possess more power and control over resources and decision-making than groups who are without power or voice. To have power, according to Marilyn French (1985), is to access a network of social relationships in which an individual or group can bring influence, persuasion, or threat to others to achieve a specific goal. Here, HIV-positive mothers are included in the latter group: those without power.

Empowerment practices also have a strong root in feminist research (Carr, 2003; Turner & Maschi, 2015). Carr (2003) and Turner and Maschi (2015) argued that women are often positioned as powerless or marginalised in their social, cultural, and political spheres. In this study, women's positionality is aligned with a critical consciousness, followed by efforts to achieve social transformation (see Carr; Turner & Maschi). Women's lack of empowerment is likely to impact their ability to make social change. Major studies of significance relating to HIV. For example, Hollen (2007) study in India, the work of Pranee Liamputtong and Niphattra Haritavorn (2014) in Thailand, and Hardon et al. (2009) in Vietnam, have exemplified key

elements that enable mothers and pregnant women with HIV to maintain their own and their babies' health by accessing PMTCT services. Such elements include having a supportive environment from their family and health workers, involvement in HIV-related NGO and other group support for women with HIV, achieving social and economic independence, and valuing their lives positively or reducing self-blame. Participants in these studies were observed in the process of social transformation and, as a result, transformation in their individual and collective experiences was achieved (Hardon et al., 2009; Hollen, 2007; Liamputtong & Haritavorn, 2014). For example, five HIV-positive women modified the lyrics of a traditional song to express their thoughts and aspirations, visually and verbally, on the importance of antenatal HIV testing at midwifery level. I was able to convey the aspirations of HIV-positive women to other groups of health workers and policymakers, by presenting the revised *Cuk Ma Ilang* song for responsive change (see discussions in Chapter 8).

In this study, it is posited that the low participation rate in PMTCT services by HIV-positive mothers and pregnant women (less than 10% of all HIV-positive mothers and pregnant women), could be the result of the powerless and marginalised position of women in their communities. Women's social experiences such as unequal sexual relations and decision-making rights, and experiences of stigmatisation and discrimination in the community and health services (i.e., PMTCT services and VCT services), are factors which make them more vulnerable to contracting HIV. For example, women not empowered or who are lacking the knowledge and negotiation skills needed to practice safe sex, may increase their risk of contracting HIV if their husbands are IDUs, practise polygamy, or have unsafe sex. However, if women get infected with HIV by their husbands, they may be blamed and even considered sinful and unworthy wives (Butt, 2015; Damar & du Plessis, 2010; Ismail et al., 2018).

Thus far, this thesis has argued that HIV-positive women are central to the aim of increasing access to PMTCT services, and has defined the relevant barriers and supporting factors needed to increase PMTCT uptake among women in Indonesia. This study focuses on the experiences of HIV-positive mothers and pregnant women accessing PMTCT services, and seeks ideas for ways to increase access. According to Carr (2003); Gutierrez (1990, 1995); Turner and Maschi (2015); Wallerstein (2006); Wang and Burris (1994), effective empowerment strategies can be achieved by encouraging grass-root voices, building a supportive environment, gaining collective engagement in programme planning, and having community members define health care needs. Turning to the next section, I discuss FPAR in more detail.

a space to share women's individual and collective voices, and experiences of their health, in all stages of FPAR, can contribute to improving the quality of women's health. They added that cultivating relationships or shared collective power and strategies is essential in every FPAR study to best utilise everyone's knowledge to address the complex nature of women's health issues. In addition, potential participants (also known as co-researchers) in any PAR study, are the main actors; this also applies to feminist-infused PAR studies. Utilising participants as co-researchers gave me the opportunity to use their insider experiences and knowledge and engage them in dialogue, individually or collectively, to learn about and discuss my research (Liamputtong & Ezzy, 2005; Lykes & HershBerg, 2012; McIntyre, 2008; Reinharz & Davidman, 1992). In this study, I therefore use the word "participants" to cover all people involved in the research.

Figure 4.1 below summarises the research cycle of FPAR in my research by adopting some principles and dimensions of FPAR based on previous literature and research by Carr (2003), Lykes (2007, 2012), Maguire (1987, 1996), Ponc et al. (2010), and Reid and Frisby (2008). HIV-positive mothers and pregnant women, their social roles, and life context, were central to this study to allow for the construction of knowledge, critical understanding of their vulnerability of HIV and their women's needs, and the individual and collective consciousness needed to improve accessibility of PMTCT services (Points 1, 2, 3 in Figure 4.1). Involving other key groups in PMTCT services, such as health workers, peer support groups (Points 2, 3, & 4) and HIV stakeholders (Point 5) facilitated the gathering of reflections from diverse insider positions in the PMTCT programmes in order to find possible collective solutions (Points 1, 2). Moving to Points 5 and 6 of the cycle, the collective awareness of the importance of PMTCT services was critically examined by all participants (from HIV-positive women to HIV stakeholders) to enable social transformation in practice. Hence, the process of social transformation ought to be generated through this creative feminist-PAR approach, individually or collectively, by considering the dynamics of gendered power relations.

Participatory visual methods were used during a series of FGDs and interviews. Participatory visual methods are considered modes of inquiry, production, and representation in the co-creation of knowledge. Participants and communities are engaged to create evidence about their own health and well-being, as well as modes of dissemination in relation to knowledge translation and mobilisation (Mitchell & Sommer, 2016). These methods allowed for participants to express their thoughts (i.e., feelings, aspirations, ideas, desires, experiences) through visual representations through visual representations such as collages of HIV vulnerability factors among women (Figure 4.2:) and puppet shows adapting traditional songs to promote improving the availability of antenatal HIV tests (Figure 4.3:). Such visual outcomes were used as key empirical evidence and data to be analysed and were powerful tools to assist the presentation of women’s ideas to other groups in the study and create space for them to expand on additional visual presentations that could be both empowering and reflective (Aldridge, 2015; Fraser & al Sayah, 2011; Leavy, 2015; Mitchell & Sommer, 2016).



Figure 4.2: A collage showing modes of HIV transmission among women of childbearing age (For explanation of this figure, see Chapter 5)

Note. Reprinted from Sehati A’s *Creative Outcomes*, by Sehati A, 2017, Palembang, Indonesia. Copyright (2017) by Sehati A. Reprinted with permission.

practice. Therefore, I prepared activities for their children and offered refreshments for all the FGDs.

Fifth, I was well prepared, flexible, and ready for unexpected circumstances. For example, I did not use my recorder during the walking interviews but did quick note taking and then typed the notes at home immediately afterwards. Furthermore, after several meetings, the participants who took the roles of PLWHIV also became more confident in expressing their ideas visually through drawings, etc. I learned that informal sessions, such as having lunch, visiting their homes, or just going along to activities with participants was an effective method for building trust.

Lastly, my positionality was important during my fieldwork, because my personal attributes, as an Indonesian woman, a mother of three children, and a lecturer in a public university, gave me more leeway to gain participants' trust. I was humbled and excited by their positive anticipation and excitement in being involved in this research.

3. Field-study design

This previous section has discussed the experience of pre-fieldwork, I will now explain the process of the fieldwork. Fieldwork was carried out from 19 March to 3 July 2017 in Palembang, Indonesia. In March 2017, I was 16 weeks pregnant. Unexpectedly, being pregnant was advantageous, as I received support and empathy from HIV-positive women and their partners, as well as stakeholders and NGOs related to HIV. Dissemination of initial findings of this study was undertaken in September and October 2018. My fieldwork started with the formulation of the research advisory group (RAG) followed by recruitment of two research facilitators, and participants in this study, groups of HIV-positive women and key stakeholders.

Formulation of the RAG

Initiating this FPAR in August 2015, prior to my doctoral studies, I had proactively contacted officers related to HIV programmes in the PHO and AIDS commission (*Komisi Penanggulangan AIDS*) in Palembang. I asked for preliminary information, HIV-related data, and books related to my research interest. I gained their support for conducting my research because they shared similar concerns related to low accessibility of PMTCT services. Additionally, I maintained my communication with potential RAG members when I wrote my research protocol in order to confirm my research plan.

My supervisors advised me to form an RAG in order to receive feedback during my fieldwork. My primary supervisor reminded me not to rush the process and advised me to work with an advisory member first on my research plan. One week after arriving in Palembang, I sought consultation with one of my potential research advisors on 19 March 2017, to discuss my fieldwork. Jaya (pseudonym) was the first member of the RAG. He was university qualified and had been working for the AIDS commission for 11 years. He had also worked in NGOs related to HIV for five years. Jaya connected me to my potential research facilitators during my fieldwork. On 11 April 2017, I met my second research advisor from the Palembang PHO. Wawan was an epidemiologist and had a postgraduate degree. He was a coordinator of a communicable disease unit at the Palembang PHO and had worked for 20 years on this board. In addition, the PHO is responsible for health programs in Palembang, including communicable diseases such as HIV/AIDS. Wawan was happy to support me, as my research would benefit PMTCT programmes in Palembang. Finally, I asked my research facilitators, Angrek and Kenanga, who are HIV-positive women and peer support workers for WLWH, to be part of my RAG and consult on my research plan (see next section, research facilitator).

In my study, my RAG members (Jaya, Wawan, Angrek, and Kenanga) provided a platform for discussing my research process and the challenges of the PMTCT programmes. They also helped me with the recruitment of health workers and peer support or outreach workers, and taking participants' knowledge to policy makers in Palembang. According to Lawson et al. (2015), gaining advanced knowledge about research and issues related to field research and the people with expertise about it is a necessary part of any PAR, particularly with research advisory members who are well positioned to address the research results strategically and effectively. In addition, previous FPAR studies also involved RAGs comprised of people from local organisations, local or indigenous people, and experts related to their research as the first step of the research process (e.g. Jategaonkar & Ponik, 2011; Lykes et al., 1999; Yoshihama & Carr, 2002).

Recruitment of research facilitators

The need for research facilitators to assist with organising meetings or discussions was discussed during the pre-fieldwork phase. My first RAG member, Jaya, made it clear I would need a research facilitator—someone who would introduce me to the HIV-positive women's communities. Therefore, he introduced me to two potential research facilitators who were peers

of HIV-positive women in Palembang. Both were women in their forties, HIV positive, spoke local dialects, and were able to commit to the time required for my research.

Both potential research facilitators had worked with NGOs related to HIV – one for about eight years, and the other, for about three years. Both were high school graduates. My first facilitator, Anggrek, was married with two adopted children, and my second facilitator, Kenanga, was a single parent with one child. Anggrek became infected with HIV from an unsterile injection, and Kenanga was infected with HIV by her late husband. Both women assisted with facilitating all meetings, some initial FGDs, and other informal gatherings with the 12 HIV-positive women.

Prior to my data collection, I arranged a meeting with Anggrek and Kenanga on 20 March 2017 in a floating restaurant on the Musi River. I introduced myself and my research topic on HIV women and PMTCT programmes. Both of them shared some of their first-hand personal experience as HIV-positive women and the experiences of stigmatisation and discrimination from health workers. This first meeting was very productive, and I learned about the community of HIV-positive women in Palembang. For example, Anggrek said that half of their peers were single parents. In addition, they said that HIV services for HIV-positive women and children were still poor. They also mentioned the current national insurance scheme launched by a former Indonesian President, Susilo Bambang Yudhoyono. Under this scheme, pregnant women had to apply to the Indonesian National Health Insurance System (*'BPJS-Badan Penyelenggara Jaminan Sosial Kesehatan'*; see Chapter 3) to cover the costs of their delivery. However, this was a problem for many HIV-positive women, particularly from rural districts, who generally only learned of their HIV status at the end of their pregnancy.

During this meeting, both research facilitators helped me finalise the fieldwork plan. We used the term “B20”, the medical term for HIV, because there were other people eating in the floating market where we met. I mapped the main points of our discussion and asked Anggrek and Kenanga to add some points to the map. Anggrek suggested to “open the door” first with these HIV-positive women by holding informal information sessions collectively or individually (see Appendix C.a.2). They argued that it was important to gain participants’ trust and build rapport with them to make them feel at ease and comfortable with me, and build a sense of ownership in the research.

Other issues were also discussed. They suggested forming homogenous groups, such as a group of single HIV-positive mothers, a group of HIV-positive married women and their HIV-positive husbands, and a group of HIV-positive married women with their HIV-negative husbands. However, it was challenging to have a homogenous group in the field because the participants had different time constraints and availabilities; therefore, two heterogeneous groups (single mothers and married HIV-positive women, with HIV-positive or negative husbands/discordant spouse) were formed, and individual meetings with seven other HIV-positive women were arranged. Additionally, possible venues for research activities were explored, such as NGO offices, public parks, local restaurants, and cafes. Some methods to encourage participants' commitments were also discussed, such as providing a token of appreciation for those who came to the FGD on time. At the end of the meeting with my research facilitators, I gave them information sheets about my study, and we created a WhatsApp group.

Recruitment of participants

There were three groups of participants: 1) HIV-positive women; 2) health workers; and 3) peer support and outreach workers. All participants were purposively recruited based on some criteria of each group. The inclusion criteria of the HIV-positive women were: 1) HIV-positive women of reproductive age; 2) living in Palembang, South Sumatra; and 3) available to join a series of FGDs or interviews. For the other groups, potential participants required women or men to meet at least one of the following criteria: 1) responsible for any PMTCT service or programme, or other HIV-related programmes in Palembang, South Sumatra; 2) have worked as an outreach worker or peer support for HIV-positive women; and 3) responsible for coordinating peer support or outreach workers for HIV-positive women.

Recruitment of HIV-positive women

Purposive sampling was used to recruit HIV-positive women aged between 15-49 years old living in Palembang, South Sumatra, and who were willing to participate for 90 minutes for each interview or two hours for each FGD. There were one to three interviews and up to five FGDs for each group. An advertisement (see Appendix C.a.3) with information about the research was circulated by my research facilitators and VCT health workers in Palembang.

The first step was to recruit participants with the help of my research facilitators. Fifteen potential participants were invited to be involved in this research after attending information

sessions individually or collectively. Ten potential participants came to the first informal session on 25 March 2017 in Taman Kota Park, and five were approached individually to attend study information sessions in April 2017. Twelve were willing to participate in the study, three declined to be involved for various reasons (about to give birth, preparing for a wedding, and fear of breaching confidentiality). Next, I recruited a further six participants from health settings. Initially, I introduced my research in a coordination meeting for VCT health workers on 27 April 2017 and asked VCT workers to share my advertisement with their networks and HIV patients. From May to June 2017, two health workers, with consent from each individual, introduced more than six potential participants.

In total, 18 women living with HIV contributed to this study. They were aged 21 to 47 years. Six were widowed and 12 were married. 15 women were raised in cities or regencies in South Sumatra, including Palembang (n=12), Lahat (n=1), Kayuagung (n=1) and Sekayu (n=1). The rest were from outside South Sumatra, including Jakarta (Betawi), North Sumatra (Medan), and South Sulawesi (Makasar), but they have stayed in Palembang between 4 to 10 years.

All except one participant identified themselves as housewives (*ibu rumah tangga*). At the time of this study, one woman, Mona was working full time. The term *ibu rumah tangga*, in Indonesian context, is a generic term used to refer to married women who were either fully financially dependent on their husbands or those who involved in informal sectors. For example, participants who worked as an hourly paid housemaid (cleaning other people's houses) or running a small *warung* (a bric-brack stall) had called themselves as *ibu rumah tangga*. Although 17 participants declared themselves as *ibu rumah tangga*, seven were fully financially dependent on their husbands and 10 had worked in informal sector, having an online business and opening a small stall. Six participants who were widows also regarded themselves as *ibu rumah tangga* even when they were the primary income-earner or the breadwinner of their families (Table 4.1:).

Among the 12 married women, six were in their second marriage, as their first husband had died. Eight women had deceased husbands who were diagnosed in the late stages of HIV. Fifteen of the women had HIV-negative children – between one to five children. The remaining women were raising children living with HIV. Two participants had delivered stillborn babies before they knew their own HIV status. In terms of the accessibility of PMTCT services, seven women had accessed PMTCT services, and three had children confirmed as HIV negative. For the other five women who accessed PMTCT during their pregnancy and after their delivery,

their children (all under 18 months) were taking prophylaxis medicine before being tested for HIV at the age of 18 months. The majority of participants owned public insurance from BPJS (Table 4.1:).

Table 4.1: Characteristics of the HIV-positive women in this study

No	Pseudonym	First CD4* (cells/mm ³)	Year of HIV diagnosis	Ownning BPJS	Age	Marital status	PMTCT access*	HIV status of husband	Number of children alive	Women's economic circumstance during the study	Education level/Women's lived	Notes
1	Mira	350	2015	Yes	21	Married	Yes	Pos	2	Dependent on husband	Senior School /Urban	High 1 st marriage, monogamous; 1 st child HIV free; 2 nd child took prophylaxis, vaginal delivery, confirmed HIV free in December 2017; Bisexual husband
2	Bulan	40	2013	Yes	46	Widow	No	Pos	1	Work outside house (have <i>warung</i>)	Senior School /Urban	High Divorced from 1 st husband; 2 nd husband deceased, was HIV pos.; 2 nd marriage, polygamous.
3	Nika	292	2016	Yes	22	Married	Yes	Neg	3	Dependent on husband	Elementary School /Rural	High 1 st marriage, monogamous; 1 st and 2 nd child were HIV free; 3 rd child was taking prophylaxis.
4	Alung	100	2012	No	37	Married	No	Neg	3	Dependent on husband	Elementary School /Urban	High 2 nd marriage as a 2 nd wife; One HIV pos. child and one-deceased child.
5	Rini	400	2011	Yes	41	Widow	No	Pos	3	Not work	Senior School /Urban	High Deceased husband was HIV pos.
6	Mawar	300	2011	Yes	41	Married	No	Neg	2	Work at home (have internet café)	Senior School /Urban	High 2 nd marriage; polygamous; 1 st deceased husband was HIV pos.; 2 nd husband HIV neg.; Former IDU.
7	Mela	300	2014	No	42	Widow	No	Pos	3	Work outside house (as a house-maid)	Senior School /Urban	High Deceased husband was HIV pos.; Husband was an IDU.
8	Nina	329	2012	Yes	32	Married	No	Neg	3	Dependent on husband	Senior School /Urban	High 2 nd marriage; monogamous; 1 st husband deceased, was HIV pos.; 2 nd husband HIV neg., 1 st husband was an IDU.
9	Mano	300	2016	Yes	25	Widow	No	Pos	1	Work outside house (barbershop)	Senior School /Urban	High Deceased husband was HIV pos.; One child was HIV neg.; Former prostitute.

10	Oneng	155	2016	Yes	41	Widow	No	Pos	6	Work outside house (as a housemaid)	Senior School /Urban	High	Deceased husband was HIV pos.; Children 1-5 were HIV neg.; Sixth child was HIV pos.
11	Sinta	-	2012	Yes	41	Widow	No	Unknown	1	No job	Senior School /Urban	High	Deceased husband never took an HIV test. Former IDU.
12	Mona	500	2012	Yes	30	Married	Yes	Neg	2	Work outside house (an administrative staff)	University /Urban		2 nd marriage, monogamous; 1 st husband deceased, was HIV pos.; 2 nd husband HIV neg.; 1 st child was HIV free; 2 nd child was taking prophylaxis. 1 st husband was an IDU.
13	Putri	292	2007	No	35	Married	Yes	Pos	2	Work at house (have <i>warung</i>)	Senior School /Urban	High	1 st marriage; monogamous; 1 st and 2 nd children were HIV free; (2 nd child was taking prophylaxis); Husband was a former IDU.
14	Maya	400	2015	Yes	33	Married	No	Neg	3	Dependent on husband	Elementary School /Rural		1 st husband divorced, was HIV neg.; 2 nd husband HIV neg.; Former prostitute.
15	Oda	290	2017	Yes	30	Married	No	Neg	3	Work at house (have <i>online business</i>)	Senior School /Rural	High	1 st marriage, monogamous; 1 st and 2 nd children were HIV free; 3 rd child was HIV pos.
16	Xani	300	2007	Yes	35	Married	Yes	Pos	3	Dependent on husband	University /Urban		1 st marriage, monogamous. Husband was a former IDU.
17	Bunga	350	2017	Yes	30	Married	Yes	Neg	1	Dependent on husband	Senior School /Urban	High	2 nd marriage, monogamous; 1 st husband deceased, unknown HIV status; 1 st child was taking prophylaxis.
18	Mulan	400	2012	Yes	28	Married	Yes	Neg	1	Dependent on husband	Senior School /Urban	High	2 nd marriage, polygamous; 1 st husband deceased, HIV pos.; 1 st child died of pneumonia, a sign of HIV; 2 nd child taking prophylaxis; Husband was former IDU.

Note: pos= HIV-positive, neg= HIV-negative; 1st -2nd -3rd and soon- the order of their children or husband. *Warung= bric-a-brac stall next to the house*

* CD4 (cells/mm³): CD4 cell count, the level of white blood cells, is frequently used to measure how long someone has been infected with HIV. PLWHIV who have a CD4 of less than 200 cell/mm³, 200-350 cells/mm³ and over 350 cells/mm³ are estimated to have contracted HIV about eight, four and one year prior, respectively (Lodi et al., 2011)

Recruitment of health workers and NGO workers

One group of midwives, doctors, and NGO workers were invited to join a series of FGDs. Twelve midwives and eleven doctors participated in FGDs. The length of their experience as health workers ranged from 2 to 30 years among the midwives, and 1 to 18 years among the doctors. Half had been working in community health centres, while the rest worked in public and private hospitals. Fifty percent of all participants had previously participated in HIV programmes and training. Most participants were female; only two participants were male (Table 4.2 and Table 4.3).

Table 4.2: Characteristics of the midwife participants

No.	Pseudonym	Age in years	Length of work experience in years	Participated in HIV programmes,	Place of work
1	Siti	30	10	Yes	Puskesmas
2	Dar	33	10	No	Private hospital
3	Nana	49	27	Yes	Puskesmas
4	Mimi	37	15	Yes	Private hospital
5	'Y'	40	10	Yes	Private hospital
6	'O'	35	13	No	Private hospital
7	Nana	34	2	No	Puskesmas
8	Oci	25	2	No	Public hospital
9	Wati	25	6	No	Public hospital
10	Linah	26	2.5	Yes	Puskesmas
11	Ditha	27	3	No	Puskesmas
12	Wi	44	30	Yes	Puskesmas

In the NGO groups, there were eight participants from four NGOs, and one from a female-focused HIV organisation. They were between 20 and 40 years old, and had between one and fifteen years of experience in the field. Their roles varied, and included peer support for HIV-positive women and outreach workers (e.g., for MSM, female sex workers, or transgender people), and social and financial support for PLWHIV (Table 4.4).

Table 4.5: Dissemination with HIV policy makers, and health and women’s organisations

No.	Activities	Expertise	Participants
1	Group Discussion 1	VCT and PMTCT team in a public hospital	4 participants ^a
2	Group Discussion 2	Policy makers	12 participants ^b
3	Individual Meetings	PMTCT team, NGO, HIV specialist	8 participants ^c (met separately)

Notes:

^a a doctor, a midwife, the head of an HIV programme, a counsellor; some of them also joined FGD with health workers.

^b four people from the PHO, five people from health organisations (midwives, nurse, and HIV counsellor) and women’s organisation (PKK or *Pembinaan Kesejahteraan Keluarga*: Family Welfare Movement), one representative from the Global Fund to fight HIV), two people from medical service in a hospital and a *puskesmas*.

^c two obstetricians, a doctor in a VCT centre, one paediatrician, one manager of an NGO, a research coordinator in a hospital, a head of medical services in a hospital, and a coordinator of communicable disease at the PHO in Palembang and South Sumatra Province.

4. Creating space with HIV-positive women in research and other groups

As noted previously, the central participants were HIV-positive women as the experts of women’s problems and solutions related to access to PMTCT services. This section discusses the implementation of FPAR in creating space with HIV-positive women and is presented in four parts. The first part overviews the data generation cycle, the second part discusses the participatory process of two groups of HIV-positive women, and the third part discusses the participatory process of the seven HIV-positive women that I met individually. The fourth part explains the response and participatory process of other groups after I had disseminated the voices and aspirations of the HIV-positive women.

Overview of data generation cycle

The application of FPAR principles in the data collection is central to the study method. Participants engaged in dialogues with the research process in a series of FGDs and individual interviews, and shared their voices, experiences, and aspirations through visual methods. Their diverse perspectives enhanced the credibility of the study results. The purpose of this initial step of FPAR was to create a safe environment and communication space for HIV-positive women to share knowledge, to critically examine their lived experiences as mothers and HIV-positive women, and any relevant context, and build a critical consciousness of their life linked to other groups in this study—the NGO workers, health workers and HIV policy makers. Figure 4.4: provides a cycle of data generation of this current research and Table 4.6 presents an

Table 4.6: Fieldwork of data generation in this research

Aim	People involved	Example of data collection method
PHASE 1: Establishing rapport and group dynamic		
To build rapport and gain trust with the participants of HIV-positive women of childbearing age To introduce the research topic and method to the people involved	HIV-positive women, the researcher, and research facilitators	Go-along (walking) meetings; visual methods; and/or traditional oral form expressions 1-2 months
PHASE 2: Building partnership and ownership of the research project		
To build a partnership and collective ownership of the research project for all people involved To share inspiring life stories of their experience with HIV	HIV-positive women, the researcher, and research facilitators	FGD, informal interview, and visual method (mind-mappings and collages) 1-2 meetings
PHASE 3: Brainstorming the problems		
To brainstorm, and illustrate the barriers in accessing PMTCT services To facilitate critical dialogue towards a critical consciousness among all people involved	HIV-positive women, the researcher, and research facilitators	FGD, informal interview, and visual method (mind-mappings) 1-2 meetings
PHASE 4: Developing the strategies		
To create creative solutions to problems and means to action those solutions To facilitate critical dialogue toward critical consciousness among all people involved	HIV-positive women, and the researcher	FGD, informal interview, and visual method 1-2 meetings
PHASE 5: Bridging the voices, ideas, and aspirations		
To link the voices, ideas and aspirations of HIV-positive women to groups of health workers, NGO workers, and finally, to groups of HIV stakeholders To promote actions and gain support from HIV stakeholders	Key informants related to PMTCT services and programmes, and the researcher	FGD, informal interview, and visual method 1-3 meetings

Collective creative works

The research began with a series of FGDs with two groups of HIV-positive women. Of the 18 HIV-positive women in this study, 11 decided to form two groups named “Sehati A” (five members) and” Sehati B” (six members). “*Sehati*” can loosely translate as “in solidarity or in one hearth we are together”. I had five FGDs with each group. Members of each group worked together starting with brainstorming the barriers of accessing PMTCT services. Then, next

'S' cycle of creative participatory of creating lyrics

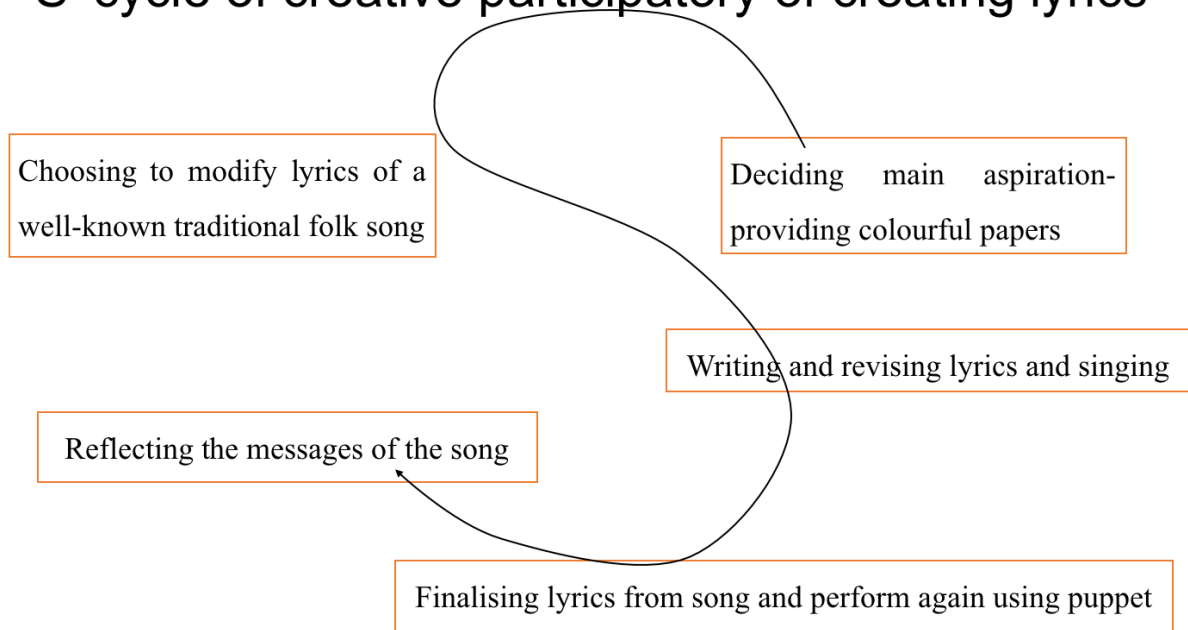


Figure 4.5: Process of creative participatory of creating modified lyrics of *Cuk Ma Ilang*

The second group of HIV positive women, Sehati B, made a drama by first developing the storylines, then working out a role play. Drama or role playing as a research technique, has been used to represent and study interpersonal behaviour such as the thoughts and feelings of individuals and groups (Robinson, 2011). The story in this study was inspired by the experiences of the two group members who had accessed PMTCT services in *puskesmas* in the early stages of their pregnancies, and delivered their babies in hospital. After rehearsing their role play, they recorded and reviewed it. They included five short story segments (scenes) in their role play, before deciding to have their final output as a puppet show. Each scene or story segment was rehearsed and reviewed separately from other segments. This process is depicted in Figure 4.6:.

'S' cycle of creative participatory of role play

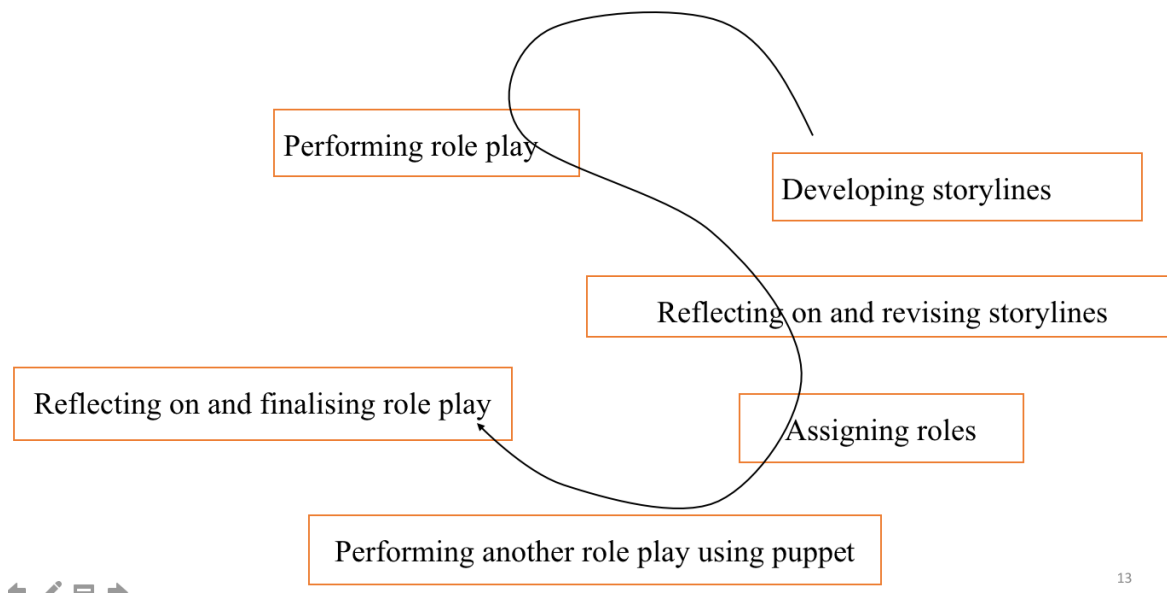


Figure 4.6: Process of creative participatory of role play

Individual creative works

Another component of the research process included ‘go-along’ interviews with seven HIV-positive women who were not comfortable being involved in FGDs. Meeting individually with them created opportunities to observe hospital treatment for HIV-positive pregnant women and HIV-positive women with their HIV-positive children who were taking prophylaxis treatment. Three of the women were able to see me several times and produced a poem, drawings, and mind-mappings (Table 4.7). The remaining four women, due to various commitments, were able to have only one interview session each. In addition, I had the opportunity to meet four of my participants’ husbands during the interviews and had informal discussions with them.

Other groups: Linking the voices and aspirations

The next step focused on connecting women’s voices and aspirations with other groups of health workers and peer support group/outreach workers, and inviting collective reflections on the life context and needs of the women versus their roles in the wider context of PMTCT services. Table 4.8 presents some creative outcomes from other participants during the dissemination process.

some original quotations or words in the source language are provided in the findings chapters to address some uniqueness across languages, as there is no single correct translation (see Temple, 2008). This process aimed to maintain the rigour of the research during data analysis. A framework of this process is presented in Table 4.9.

Table 4.9: Rigour checklist in the data analysis

Criteria	Rigour checks for language awareness
Credibility (Internal validity)	Data collection processes take into account the preferred language of participants Transcription and analysis of data is completed in source language Standard translation procedures are performed for selected quotations, codes and themes Original quotations or words in source language might be provided in presentation of results Supervisors review and critique data analysis to obtain diverse perspectives and viewpoints
Transferability (External validity)	Details of the language profile of participants: Palembang and Indonesian
Dependability	Inquiry audit of researcher's field notes Description of visual outcomes Reflection notes by bilingual supervisors
Confirmability (Objectivity)	Audit trail of data sets by bilingual supervisors

(Adapted from Irvine et al., 2008)

Note: Definition of rigour criteria: Credibility (internal validity) is “confidence in the truth of the data”; Transferability (external validity) is “the extent to which the findings from the data can be transferred to other settings or groups; Dependability is “the stability of data over time and over conditions”; and Confirmability (objectivity) is “the objectivity or neutrality of the data”. (Irvine et al., 2008, p. 45)

Thematic analysis was performed by applying the steps set out by Saldana (2016) and Terry, Hayfield, Clarke, and Braun (2017) all data (example group discussion transcripts, field notes, and visual outcomes [mind maps, drawings, and collages]). First, familiarisation with the data entailed reading the transcripts multiple times to immerse myself in the data. I confirmed my transcriptions with my field notes and relevant visual images during the readings. Second, coding and recoding were performed manually to find patterns, and to filter and analyse the data based on my own lens, and discover meaningful phrases and ideas. To gain a better understanding of the emerging themes in the data, I carried out first-level and second-level coding. I coded data in the transcripts twice, to ensure my emerging themes reflected the meanings held in the data. Third, categorising was performed as a process of dividing, grouping, reorganising, and linking codes to make meaning and enhance understandings of the data. Deep reflection and revising coding refined the data to categories that could then be linked

letter was needed to access some hospitals in South Sumatra to recruit participants. Additionally, a permission letter from The National Unity and Politics (*Badan Kesatuan Bangsa dan Politik*) (KESBANGPOL) in Palembang (Appendix B.c) was obtained to conduct research in South Sumatra.

As the research involved a group of HIV-positive women who are vulnerable to experiencing discrimination from wider society due to their HIV status, this research ensured that respect for their vulnerabilities was reflected in the information sheets (Appendix B.a1-Ba4), and confidentiality and privacy for participants was explained at the beginning of the data collection process. Informed and voluntary consent were described and obtained through the use of signed consent forms (Appendix B.b). All interested participants were invited to attend the first information session about the research individually or collectively. Then, participants who agreed to take part in the research were asked to sign a consent form before the data collection process.

Within Indonesia's bureaucracy system, other groups—NGO workers, health workers and HIV policy makers—received a formal letter from the Dean of the Public Health Faculty at Sriwijaya University, my direct line manager, to invite potential participants through their institution leaders (such as in hospitals, NGOs, Palembang PHOs) to join my research, a participant information sheet (Appendix B.a5-Ba8) and consent form (Appendix B.b) and consent and release form (Appendix B.b). Additional inclusion criteria such as midwives and doctors from community health centres and hospitals in Palembang were stipulated. Once their leaders had consented to participate in the research, I discussed with their leaders, how to set up a meeting date, time, and place for interviews or FGD.

Protection of participants

Protection of participants from any deceit, harm, and coercion was taken seriously in this research. It was essential to be able to keep to the cultural values, social, and ethnic diversities of the participants. Protection of participants was implemented through the following processes. Firstly, participants' privacy was maintained through the removal of their personal details from all data and reports; all publications and presentations in the future will also use pseudonyms. Of note, when relevant, participants were asked to choose their own unique identifier. Secondly, throughout the data collection stages, I informed participants that their participation was voluntary and they were able to leave at any time without negative consequences. Thirdly, plain local language was used at all time to ensure that participants felt



Figure 4.7: Puppet show for role play with a group of HIV-positive women

Note: Reprinted from Sehati B's *Creative Outcomes*, by Sehati B, 2017, Palembang, Indonesia. Copyright (2017) by Sehati B. Reprinted with permission. English translations: *dokter* (doctor), *suami* (husband), *ibu hamil (+) HIV* (HIV-positive pregnant women), other women in this figure, nurse and hospital administrative staff.

7. Summary

The research paradigm and methodology described in this chapter guided me through my pre-fieldwork and fieldwork. Figure 8 presents a diagram of the research process starting from feminist research as an epistemology that informed my study to focus on empowerment in feminist research as my theoretical framework and FPAR as my methodology. To support my fieldwork, I applied data collection methods such as FGDs, 'go-along' (informal) interviews, participatory visual methods, and observations, followed by data analysis through to thematic analysis and a reflection process.

I reflected on each step of my data generation. Experiences during pre-fieldwork provided insights for adjusting my research plan and tools. The initial steps were: formulation of the RAG, recruiting research facilitators, and on-going consultation with my advisory group and supervisors. After the initial steps, I recruited three main groups of participants: HIV-positive women, health workers, and peer support group/outreach workers, all of whom gave me a deeper and dynamic understanding about the richness of knowledge construction and power dynamics within groups, as well as insights into how to generate diverse solutions from the insider position of my participants. I learned that building trust and rapport and creating a safe space for each group of participants to construct critical knowledge and reflect on their situation was the key to women's active participation in this research. I was aware that women's voices

and experiences were central to obtaining knowledge on barriers to PMTCT access and solutions to improve PMTCT service access and utilisation.

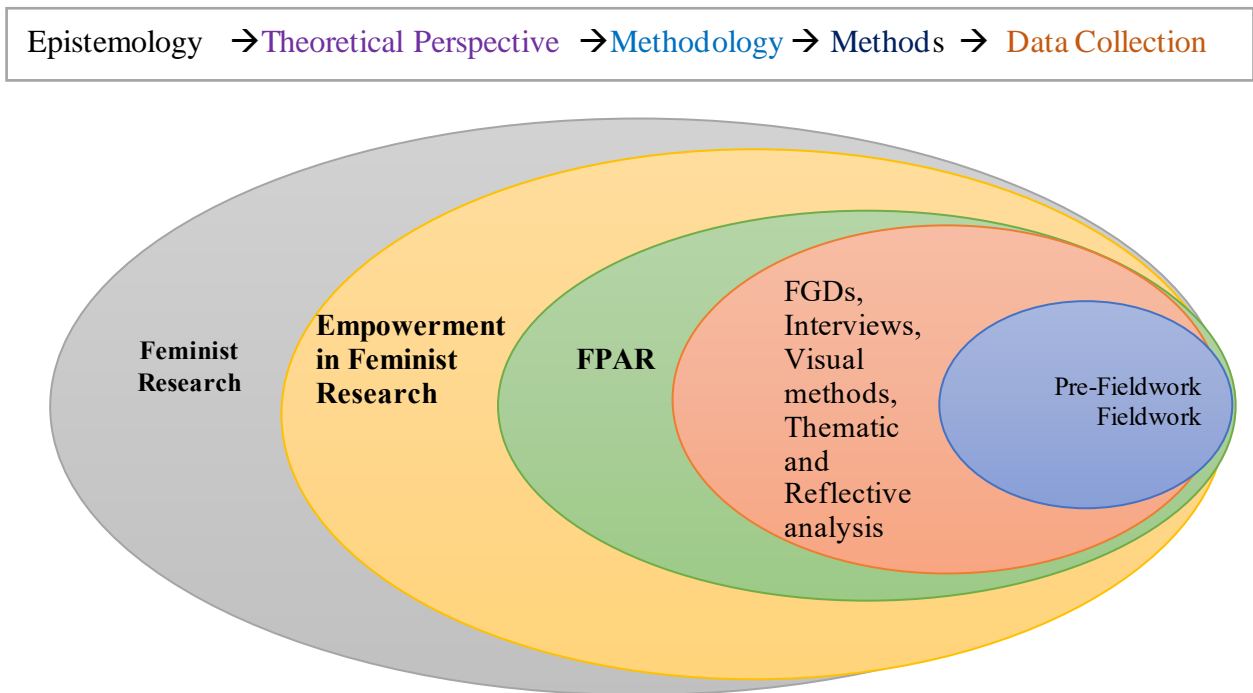


Figure 4.8: Research onion diagram to describe the positioning of the research

(Adapted from Saunders et al., 2012).

I gained valuable insights on the importance of the dissemination process through informal meetings and delivering women’s voices and lived experiences through their creative visual outputs. Engagement of HIV policymakers and health and community organisations is one way to empower these groups to get involved through social transformation to enable more women of childbearing age and (pregnant) HIV-positive women to access comprehensive PMTCT services. I believe that participatory visual outputs will travel beyond my research journey and the outputs will have an ongoing impact on the empowerment of women’s voices. The most important part of this data collection, for me, was that my supervisors always reminded me about the methodology that I used—FPAR—to maintain credibility of my research: to learn to listen and listen to learn, and to provide a space for my RAGs, research facilitators and my participants to construct the knowledge together.

Through my journey as a novice feminist participatory action researcher, I extended the principles of FPAR into five main points. They are: (1) to cultivate trust with marginalised

Chapter 5. The life context of HIV-positive Indonesian women

Please God don't take my soul... please for my children I shall live (Oneng, an HIV-positive widow with six children; her youngest child was HIV-positive).

This chapter presents the unique experiences shared by three HIV-positive women—Mawar, Oneng, and Mira. Their experiences of HIV and pregnancy show the complex story of transmission. The first section is about Mawar, a woman with financial independence and a challenging life following her divorce. As a young divorcee, fearful of bringing shame to her parents, she decided to go to Jakarta, where she experimented with drugs and had multiple sexual partners. As a result, she contracted HIV. The story of Oneng, a married woman and mother (*ibu rumah tangga*) of six children, is discussed in the second section. Oneng contracted HIV from her husband who died just a few days after being diagnosed as HIV positive. Sadly, Oneng only knew her HIV status after her youngest daughter was diagnosed HIV positive, a year after her husband's death. The third section presents Mira's story. Mira was diagnosed with HIV and syphilis during her second pregnancy. She made an effort to minimise HIV transmission to her baby and sought a caesarean operation in a hospital as part of the prevention of mother-to-child transmission of HIV through PMTCT services. Mira was married to a man who had unsafe sex (without protection) with men. The fourth section highlights the complexity of HIV among Indonesian women who are at risk of mother-to-child transmission of HIV: a complex story I refer to as a spider's web.

This chapter explores the diversity of voices, needs, and stories of the women. There are common themes in the stories of the 18 participants that contributed to the complexity of HIV vulnerability among Indonesian women: self-perceived low risk of HIV infection, deception within marriage related to a partner having past HIV high-risk behaviours, norms in health practices for HIV, and silence and normalisation of discrimination against PLWHIV. The main points in this analysis are how FPAR methods assisted in identifying women's HIV vulnerability from the complex intersection of life experience, the hegemony of masculinity, heterosexual morality, and the social and cultural values and norms that are embedded within religious (Islamic) and social teachings in Indonesia. These women's health-seeking behaviour cannot be separated from their diverse socioeconomic statuses, ages, and their knowledge and experiences related to HIV. A non-integrated and uncoordinated health system also contributed

status to him, Mawar did not answer straight away. Instead, she opened the question to others in her FGD group:

How about you all [she pointed to other HIV-positive women in her focus group]. Were you brave enough to disclose your HIV status to someone who loves you and wants to marry you? Would no one be brave enough, or would you? (Mawar)

Non-disclosure of her HIV status prior to her second marriage

Mawar did not disclose her HIV status to Udin prior to their marriage. Only after feeling confident in Udin's love, Mawar told him about her HIV status, saying "if you are afraid of my HIV status, you may leave me". Initially, Udin was gravely disappointed and felt trapped as he lived in Mawar's house and both of them had been sexually active prior to their marriage. However, he decided to proceed with an unregistered marriage (*nikah sirih*⁶¹) with Mawar. Up until the time of this research, Udin had been afraid to take an HIV test. Of concern, however, was that Mawar and Udin did not use condoms during sexual intercourse, and Mawar had opted for injectable contraception.

Udin...my husband, whenever he felt very sick, he was always refused to doing any HIV test. He said he was scared if the result was positive that it would impact on his psyche. (Mawar)

Five days before I finished my fieldwork in Palembang, I arranged a social visit (*sanjo*⁶²) to Mawar's house. She told me that she had become aware that Udin had had multiple sexual partners, including his first wife and ex-fiancée. Udin had been dishonest with Mawar as he had never officially divorced from his first wife, who lived in another suburb outside Palembang with their two children. Udin had also had another sexual partner, Yasmin, whom he planned to marry at the end of 2017. According to Mawar, Yasmin was a divorcee and very promiscuous, and liked to party at nightclubs. Mawar called Yasmin a *pelakor*⁶³ or *perampas laki orang* (English: a woman who steals another woman's husband). Mawar believed that

⁶¹ *Nikah Siri*: an unregistered marriage performed under Islamic Law (Sharia) and not registered in the civil office or the religious department or KUA (see Chapter 2).

⁶² *Sanjo* (in the Palembang local dialect) is a social visit to family and friends following the fasting month of Ramadhan.

⁶³ In infidelity between a married man and a woman, "the use of *pelakor* in isolation reveals our tendency to blame only the woman in an affair, though it obviously takes two to tango. We must not forget the fact that there are (at least) two parties involved in any instance of infidelity" (Martin-Anatias, 2018a).

roles of women as wives and mothers (Parker & Creese, 2016; Parker et al., 2015). A young divorcee is often seen as having the freedom to engage in intimate relationships with other men without worrying about losing their virginity. Married couples are threatened with negative prejudices surrounding young divorcees who are often considered sexually available and promiscuous (Parker & Creese, 2016; Parker et al., 2015; Suryakusuma, 1999). Therefore, “divorcees typically experience more shame and more sexual innuendo than widows” (Parker et al., 2015, p. 42).

Deception within marriage

A second tension in Mawar’s story was the deception within her marriage. There were several consistencies regarding the complex modes of HIV transmission among the people in Mawar’s story. Sam, Mawar’s first husband, had secret visits to commercial sex workers during his business trips, while Udin lied to Mawar about his first marriage, as he never officially divorced his first wife. Udin’s affair with Yasmin was also hidden from Mawar. Across these deceptions, all parties—Sam, Mawar, and Udin—were actively trying not to lose face (*jaga muka*), but to depict a harmonious monogamous marriage. Illicit sexual relationships were part of the daily lives of Sam, Mawar, Udin and perhaps, Yasmin. Their sexual relationship practices were far from reflecting the ideal heterosexual marriage commonly depicted in a harmonious Indonesian family.

Deception within marriage may result in spreading HIV, and impact the mental health of a married woman such as Mawar. Polygamous marriages, without the permission of the first wife, such as in the case of Udin, are widely practised in Indonesia. Although the practice of polygamy is legal in Indonesia, the practice has been restricted and discouraged by Indonesian marriage law, particularly for public or civil servant men in government institutions (e.g. Udin). However, the practice of secret and unregistered polygamous marriages (*nikah siri*) is widespread and growing across all parts of Indonesia (Nurmila, 2009). Mawar had no intention of divorcing Udin, as her relationship with him gave her financial independence. She had been very forgiving of Udin and always accepted him back, despite her unhappiness. Mawar wanted to make her second marriage work and might not want to get divorced for the second time, as repeated divorces would lead to more social condemnation (Parker & Creese, 2016; Parker et al., 2015; Suryakusuma, 1999). Astbury (1996) argued that cultural norms and women’s social position may impact on women’s lives and mental health, and women may conform to the cultural ideal of marriage and family notions, disregarding their own needs and health. For

may have contracted HIV about eight years ago or before or during her pregnancy with Aliya (see Lodi et al., 2011).

Oneng was grateful: “*Alhamdulillah* (thank God) that my other five children are HIV free”. After the HIV test, feeling gravely depressed, Oneng locked herself in her bedroom and cried for three days and three nights without food. Her children kept lifting up her spirits and she eventually found her will to survive and raise her children. She expressed “please God, don’t take my soul... please for my children I shall live” (Oneng).

Oneng’s married life

Oneng recalled her married life with Suleman for me. Oneng and Suleman decided to live separately between 2013 and 2014, but Suleman refused to divorce her officially. Oneng always suspected that Suleman had sexual relationships with other women, which she referred to as “WIL” (*Wanita Idaman Lain*), meaning ‘another woman of his dreams’. Additionally, he had had sex with commercial sex workers without protection. Oneng believed that Suleman had used injected drugs, including methamphetamine (*shabu*), since 2003. Oneng recalled having a happy family life for the first decade of her marriage, but it declined after her husband was promoted at work. Oneng said, “my deceased husband was on the top his career back then and he started to neglect his wife and children”. Unfortunately, Oneng’s husband did not let her use contraception. Oneng’s mother-in-law, however, was very supportive and took Oneng to a nearby clinic to get injectable contraception for one year. It was after that year, that she had Aliya, her youngest child.

Suleman’s sickness

Suleman fell seriously ill during their separation (2013-2014) due to tuberculosis, which was later found to be related to HIV. Suleman was not compliant with the tuberculosis medication schedule and became very sick again. Suleman was never offered an HIV test. In 2015, Suleman asked Oneng to take him back and look after him. Out of pity, Oneng agreed on one condition: “I would take care you if you stopped using illicit drugs”. Suleman was gravely ill and very thin when he moved back into Oneng’s house; she helped him get the best medical treatment possible. Suleman was referred to a bigger hospital and was confirmed as HIV positive. A health worker asked Oneng about Suleman’s past sexual behaviour, asking “whether had your husband used to see prostitutes”, but Oneng kept silent and did not provide any answers. Suleman passed away within 10 days of hospitalisation. Of concern, however,

values as a mother and wife include looking after the wellbeing of her children and husband. Nevertheless, social morals and cultural expectations of married women are not constructed for husbands, as “sexual promiscuity for men is often interpreted as health, masculinity, and virility” (Bennett, 2015, p. 149). As a result, Oneng may have been discouraged to refuse sexual contact with her husband, in line with being obedient, although she was aware of Suleman’s infidelity and drug use. Oneng also considered that marriage as a presumed consent for her husband’s sexual needs. After two years of separation, Oneng still conformed with the societal gender norms of an ideal family consisting of a mother, father, and children, and decided to be a wife by caring for her husband who had a chronic lung disease which was later found to be related to AIDS. With poor awareness of HIV risk from Suleman’s high-risk behaviour and her HIV’s biological and physiological vulnerability (using hormonal contraceptive methods, exposing to HIV before/during her pregnancy or after her delivery, and mix-feeding of Aliya), HIV spread from her husband to Oneng and then from Oneng to Aliya. Oneng and Aliya were innocent victims who stayed alive and survived with HIV in their bodies after Suleman’s death.

Being naïve and powerless

Oneng’s narrative portrayed problems due to her naïveté and lack of power - the second tensions of Oneng’s story. Arguably, Oneng was naïve to accept her husband back into the home after being betrayed by him. She also maintained Suleman’s dignity in the public sphere (such as the hospital), by keeping silent about his multiple sexual partners. On the other hand, Oneng may have been powerless in terms of her marital disharmony when she tried to save face (*jaga muka*) in public to maintain her role as a good wife and mother. Informing on a husband’s infidelity to other people was usually interpreted as a wife’s inability to remain sexually active and meet her husband’s needs, resulting in her husband’s unfaithfulness. Dealing with these tensions, being naïve and powerless, combined with the lack of HIV testing in midwifery clinics and hospitals, Oneng’s story revealed three missed opportunities for early diagnosis and prevention of HIV of Oneng and Aliyas during: first, her regular antenatal check-up in private midwifery practice during her pregnancy of Aliya (2009); second, the tuberculosis treatment of Suleman (2014); and third, diagnosing of HIV of Suleman before his death (2016).

This section provided an in-depth understanding of how a married woman can contract HIV from a husband practising unsafe sex with multiple partners and injecting illicit drugs. Unfortunately, due to the lack of available HIV testing at midwifery clinics, poor awareness of HIV among married women, and the requirement to be an obedient wife, both Oneng and her

Key timeline of Mira

Table 5.3: Mira's timeline

2014	Mira marries Kuyung.
2015	Mira and Kuyung's first child is born.
2015	Mira and Kuyung are diagnosed with HIV and syphilis; concurrently, Mira becomes pregnant for the second time.
2016	Second child (Toleh) is born.
2016-2017	Toleh is not breastfed and is given a course of prophylaxis preventive medicine.
2017	Toleh is confirmed free of HIV at the age of 18 months.

Preventing mother-to-child transmission

Mira recalled the time when she started to feel she was going into labour. Her pain was excruciating, and the contractions came closer to each other. Psychologically, she worried that her baby would be infected with HIV during delivery. Accompanied by Kuyung, she rushed to the emergency unit at a public hospital. Upon admission, she reported her HIV status: "I am HIV positive, I need a caesarean operation." The admission nurse, however, did not believe her, so Mira insisted the nurse contact the Voluntary Counselling Testing (VCT) centre where she and her husband had been treated for HIV. The nurse contacted the VCT centre and received confirmation of her HIV status. Mira was scheduled to have the caesarean at 10 pm, the last operation of the day, meaning she had to wait about eight hours.

During the waiting time, at about 6 pm, Mira felt her contractions intensify, but the nurses kept telling her that she would be fine. Two hours later, at about 8 pm, Mira delivered her baby naturally. She felt very tired and shaken (*bergetar*), and after her delivery she realised she had not had any meals or drinks since 2 pm, in preparation for surgery. Following the delivery of Toleh, Mira's baby, both mother and baby were transferred to the maternity ward and shared an in-patient room with other female patients. They stayed in one of the lowest rate (cheapest) or third class maternity rooms for a few days or *ruang rawat inap kelas tiga*⁶⁴; her hospitalisation was covered by her public insurance (*BPJS*) (see *BPJS* in Chapter 3).

⁶⁴ Universal health coverage is an on-going process in Indonesia. To access public health care, every patient should have public insurance (*BPJS*), which needs a monthly payment in order to access 'free' health care. The in-patient facilities in Indonesian hospitals are generally divided into different classes: VIP (Very Important Person), first class, second class, and third class. The lowest monthly payment for insurance provides for the lowest class of in-patient room (Agustina et al., 2019)

taking care of her HIV-positive sister at home was very low. Later, Mira was able to recall an incident following her vaginal rashes. A year prior to her problem, Kuyung had told her about having genital itching and there were reddish-brown sores around his genitalia. Rumours within Mira's social network, suggested Kuyung had had sexual relations with men, before marrying Mira.

Men having sex with men (MSM) and pressure to marriage

To gain a further understanding of MSM in Palembang, I decided to seek more information, and met with HIV specialist health workers, peer support workers, and outreach HIV workers who had been working with MSM communities. Listening to the lived stories of insiders, I became aware that the life of MSM in Indonesia may differ from MSM in other countries such as New Zealand, where, as I observed during my time there, people had the freedom to openly express their sexual identity. MSM may contract HIV through unsafe sexual practices, but still have a relationship with a female partner. However, the majority of MSM do not disclose their sexual orientation and HIV status to their male and female partners. The following four quotations related to MSM in Palembang are from insiders.

There is a female doctor who was shocked and depressed on her HIV diagnosis, then she passed away after a few days of her hospitalisation. She may contract HIV from her husband who is also a generalist practitioner, HIV positive, and a *LSL (Lelaki Suka Lelaki)* or MSM. My worry was that her husband is still pursuing his medical education in [as a] surgeon and we cannot disclose his HIV status to others. (Medical doctor with 12 years of experience treating HIV-positive clients, go-along interview)

That woman still lives with her husband, but she had an affair with my friend, an MSM. (Outreach worker of NGO for MSM, FGD)

Some of my patients were young gay men who also were students from prestigious universities and other tertiary institutions in Palembang. One of them had a relationship also with a widow. (Nurse, a counsellor with 10 years' experience, go-along interview)

Yesterday afternoon, my friend, a gay man, just phoned me to inform me that he has got married, but his wife did not know about his HIV status. I explained to him that he can potentially spread HIV to his wife and his child. Sadly, he did not access ARV therapy to control the virus in his body. (Female peer support worker of PLWHIV, online interview)

I sought further information in a meeting with Toni, an outreach worker for HIV prevention in MSM communities. According to Toni, an MSM in Indonesia is likely to have multiple sex partners. To satisfy his parents, an MSM may decide to marry a woman, but after getting

HIV-positive woman, Mira adhered to ARV therapy and accessed prophylaxis treatment for her child. Her anxiety was released after her son Toleh, was confirmed free of HIV. I suggest that Mira and Kuyung's life was embedded in their 'perception of susceptibility' of HIV transmission to their child, and Mira's experience of caring for her sister with HIV (see Davidson, 2015); consistent with the notion that a 'good' mother protects her child from HIV transmission, was the protestation that "HIV is enough for us, [but it is] not for our children (FGD with a group of five HIV-positive women)".

To summarise the narratives of Mira, preventing HIV among MSM is complex, as their sexual practices are perceived as immoral and sinful. Consequently, this may actively prevent MSM from seeking HIV testing or disclosing their sexual orientation to their wives or other female/male sexual partners. Being MSM, according to Stephen et al. (2015), was considered a lifestyle by participants, and they wanted to "give up" being an MSM and become 'normal'; that is, adhere to heterosexual normality in Indonesia, by getting married. As a result, unsafe heterosexual and homosexual relationships, a long period of asymptomatic HIV (5-10 years), and deception within marriage may result in a 'silent' HIV epidemic among young, married women. Later, if the woman becomes pregnant, HIV is more likely (20-50%) to be transmitted vertically from an HIV-positive pregnant mother to her baby if she does not access an intervention such as PMTCT services (De Cock et al., 2000; MoH, 2012a; Tudor Car et al., 2011). Another threat in the complexity of HIV transmission is a new mutation of the HIV virus, which is more likely to occur in Indonesia, as seen in a recent study case among MSM in China (Wu et al., 2013).

4. HIV and pregnancy: A complex story of transmission

These three unique, lived stories, provide a complex "spider's web" of women's vulnerability to HIV in the Indonesian context. This section attempts to show how the four interlinked spheres—individual, intimate (marriage/family relationships), community and policy—lead to HIV vulnerability among Indonesian women. Information from the group of HIV-positive women and the collages of HIV vulnerability amongst women of childbearing age that were developed by groups of HIV-positive women in this study, allowed me to acquire, describe, and analyse a web of complex interconnected ways and experiences of HIV transmission (see Figure 5.1).

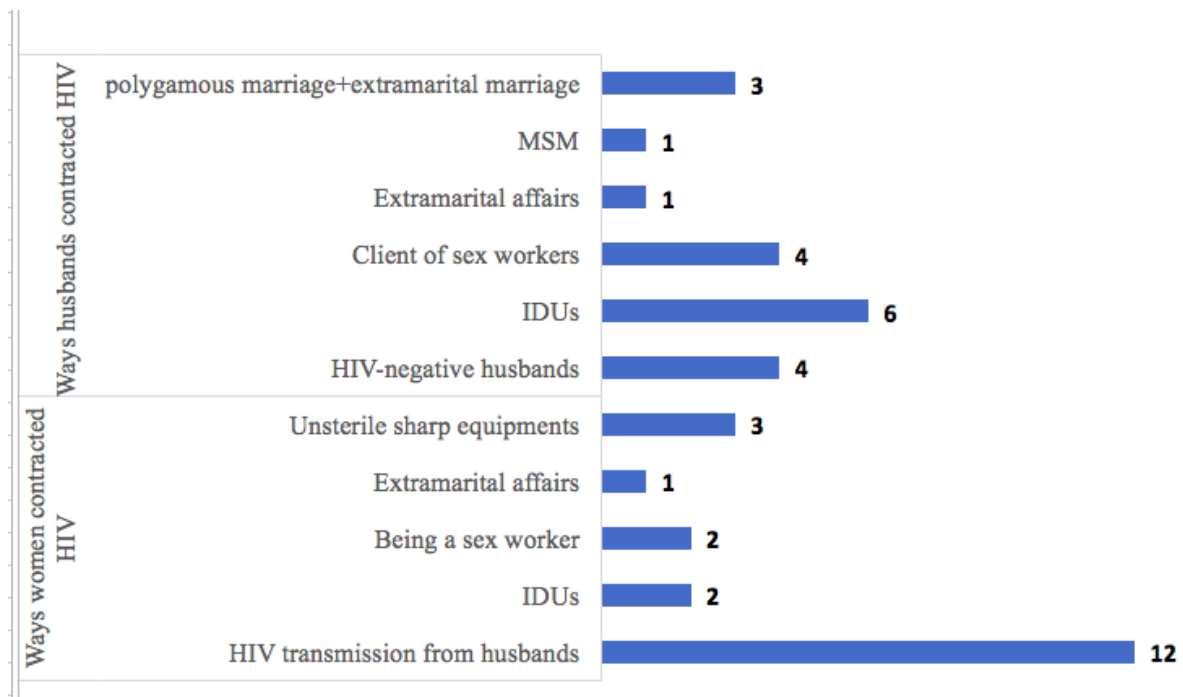


Figure 5.1: How the HIV-positive women in this study believe they contracted HIV (n=18)

Note: Some may include multiple responses, and among IDUs, women and men get HIV from sharing needles and syringes

The complexity of HIV transmission: Collective knowledge

The second part of the complexity of HIV transmission in Indonesia is based on collective discussion within diverse groups in this study. One example is a work of a group of six HIV-positive women drew pictures of the complexities of HIV transmission in Indonesia (Figure 5.2). Participants reflected on their knowledge through a collage, based on their own and their peers' experiences of how they contracted HIV. First, a husband (*suami*) might get married to a *soleha* (a good woman) who has been infected with HIV from a former HIV-positive husband or partner. This woman may have contracted HIV from her former husband, an IDU (*penasun*) or had extramarital marriage without safe sex practices. Second, a husband might get infected with HIV from female sex workers (*pekerja seks*) and transmit HIV to his wife, while female sex workers might contract HIV from their boyfriends (*pacar*) or husbands.

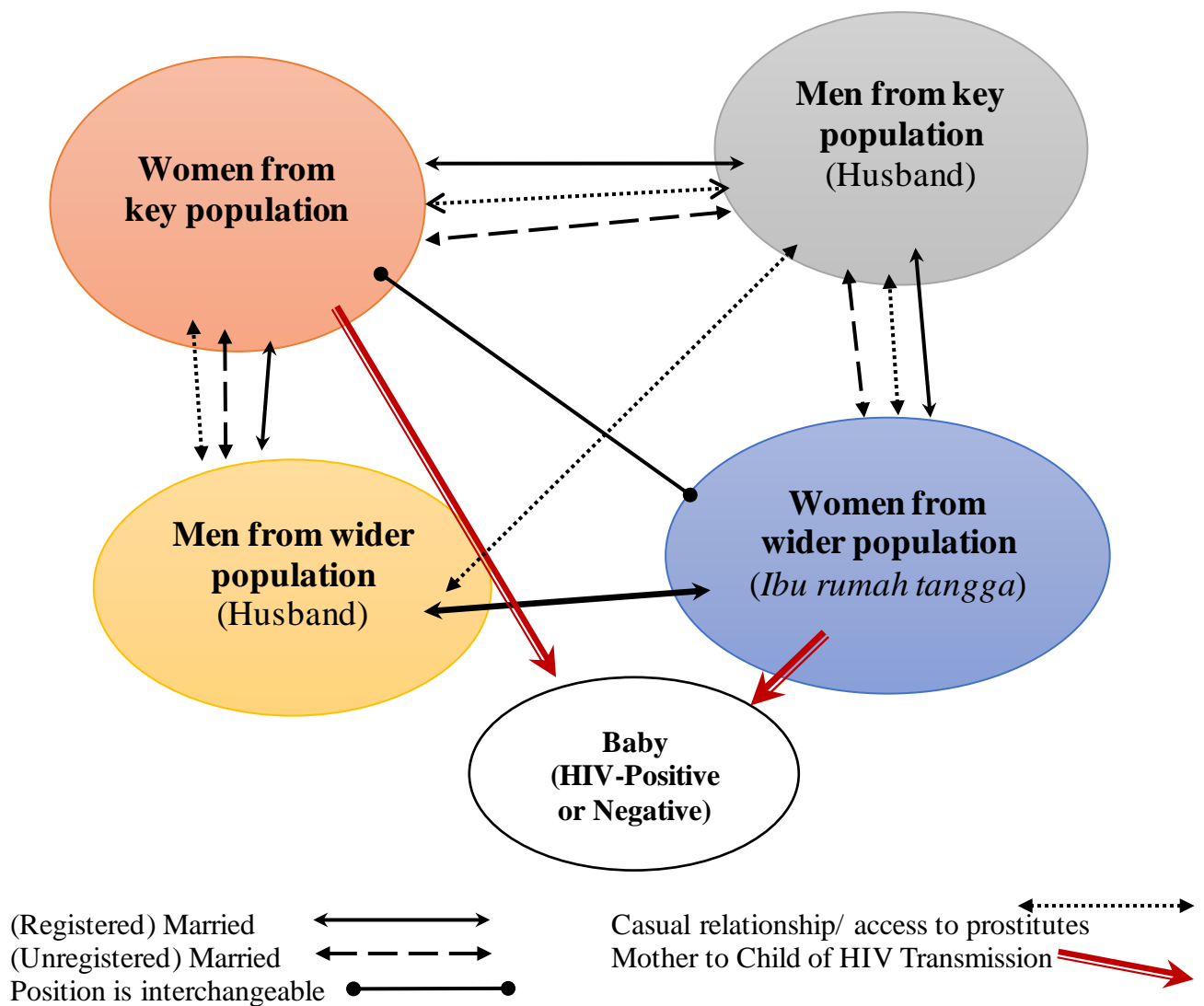


Figure 5.3: The spider's web of HIV transmission among heterosexually married women and men in Indonesia

Notes:

- Male key population: unprotected sex MSM, IDUs with no access to sterile injecting equipment, client of sex workers with low condom usage, mobile men to other provinces, and men with extramarital affairs and unprotected sex among stable serodiscordant couples.
- Women from key population: sex workers with low condom use, female IDUs, and women with multiple sex partners.
- Women in wider population: married (both registered and unregistered by the Indonesian marriage law) women

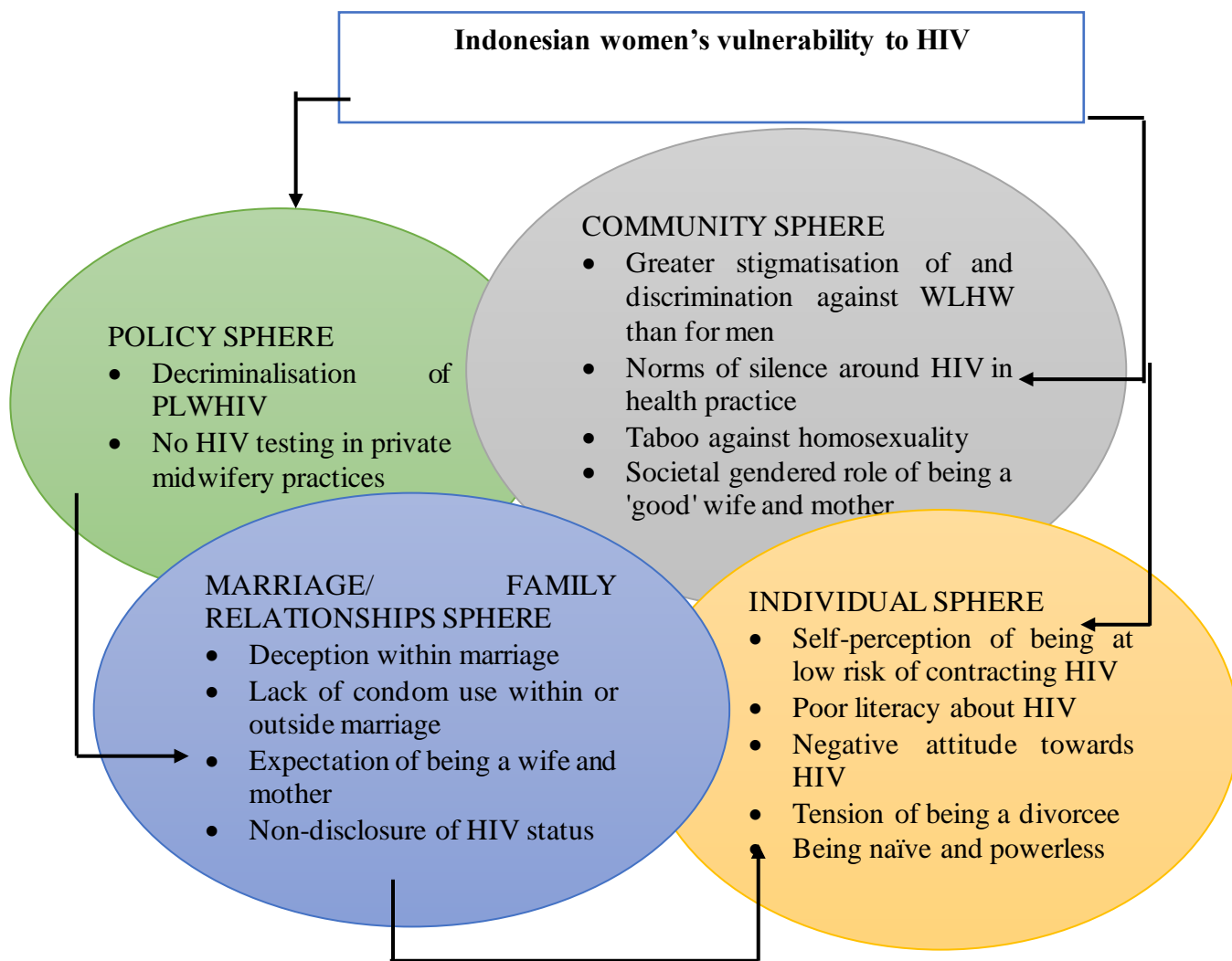


Figure 5.4: Multiple layers of factors influencing Indonesian women's vulnerability to HIV

This spider's web of transmission and infection in Figure 5.3 suggests that HIV vulnerability among women is also interlinked with gendered morality issues, heterosexual hegemony, and the value of marriage and motherhood in the Indonesian patriarchal culture, as showed in Figure 5.4. HIV transmission occurs amongst married women and men in a number of ways. Men who participate in what are framed as high-risk behaviours (for example, sharing unclean needles and syringes among IDUs and having unsafe sexual practices with sex workers or their male partners) risk contracting and transmitting HIV to their spouses and partners. Men who contract HIV through these behaviours often knowingly transmit HIV to their wives. Married men may have affairs or indeed marry other women without the knowledge of their other wives (Nurmila, 2009; Nurmila & Bennett, 2015). In addition, in a heteronormative country such as Indonesia, men who are MSM (i.e. homosexual) are pressured to marry women, but may

Chapter 6. Barriers to accessing PMTCT services

1. Introduction

Chapter 5 examined the complex story of HIV transmissions among Indonesian women, particularly *ibu rumah tangga*, and highlighted the finding that every Indonesian woman needs to be made aware that she is at risk of contracting HIV. Chapter 5, however, focuses mainly on the narratives produced by the 18 HIV+ women and a few health workers and NGO workers, to best illustrate examples of lived experience of being a mother, a wife, and an HIV-positive. This chapter explores what happens once women know that they are at risk of, or have HIV, and explains the barriers to accessing PMTCT services for women of reproductive age with, or at risk of getting, HIV. This chapter focuses mainly of voices on the health workers and a few HIV-positive women and NGO workers, to best illustrate examples of the barriers to PMTCT access.

Different participants (HIV-positive women, healthcare professionals [midwives, general practitioners, and obstetricians] and NGO workers) shared their experiences. The analysis honours the experiences of women and draws on other voices, where necessary, to gain in-depth understandings of women's journeys as they try to access PMTCT services. Interviews, FGDs, and visual methods allowed the participants and me to reflect on their life stories. This chapter is divided into three main sections: 1) Getting tested or not; 2) HIV-positive: women's experiences after diagnosis; and 3) Gendered morality: how discrimination impacts on women's access to PMTCT services.

The first section, 'Getting tested or not', reveals the story of an HIV-positive woman (Nika) who had been expelled from her village after accessing HIV testing during her third pregnancy. The analysis focuses on how breaching confidentiality of HIV results and a lack of professionalism in healthcare workers may be barriers to accessing antenatal HIV testing. The second section, which explores the experience after an HIV diagnosis, presents and analyses the story of a pregnant woman (Ani) living with HIV, who twice missed an opportunity to prevent HIV transmission to her infant during pregnancy and delivery. Ani's story provided an in-depth understanding of how fears and avoidance along a continuum (*menghindar secara terus menerus*) in dealing with HIV-positive patients and bureaucratic referral procedures failed her, when she tried to exercise her right to access comprehensive PMTCT services. The

married at 16 years. Her husband, Maman, was eight years older than her and worked as a seasonal construction worker (*buruh bangunan*) (Najmah, Andajani, & Davies, 2020).

I reflected on the breaches of privacy and confidentiality, Nika's confusion and dissatisfaction with the services, as well as the stigmatisation and discrimination she suffered from health workers and her communities. During my fieldwork, I presented Nika's story to different groups of healthcare workers, including NGO workers, midwives, medical doctors, and HIV policymakers to help them better understand the challenges of implementing antenatal HIV screening. I suggest there are two potential barriers that strongly discourage women for accessing the services: 1) breaches of confidentiality; and 2) a lack of professionalism in healthcare settings.

Breaches of confidentiality

Medical information for each patient is recorded and accessible by healthcare professionals within a health setting to provide a safe environment for other people in the healthcare facility, and to provide better patient care. Professional healthcare workers need to regard the confidentiality of their patients as a priority. Information about HIV patients, recorded at the community health centre, is sent to the provincial PHO (*Dinas Kesehatan*) and then to the national online integrated HIV-AIDS information system or *Sistem Informasi HIV-AIDS* (SIHA) (Ignatius, 2010; MoH, 2014d).

According to the Indonesian MoH Regulations, it is not ethical to disclose patients' information without their approval (MoH, 2014d). However, if necessary, a health worker or counsellor of an HIV patient can share the HIV result of their patient to other healthcare professionals who treat the patient, and to peer support workers, drug watchers (*pengawas minum obat*), a close family member, sexual partners, and other institutions that are governed by the law [*Permenkes* number 74 in 2014, Guidelines of HIV test and counselling] (MoH, 2014d). The breach of Nika's confidentiality in health setting was justified by some of the stakeholders. Two reasons were given: the practice of the culture of being nosy (*kepo*), and the health workers' intention to protect her colleagues.

The culture of kepo

As seen in Nika's story, a midwife gossiped with Nika's neighbours and colleagues about Nika's HIV status. All stakeholders in my group discussion were aware that the culture of *kepo*,

professionals in my study also reflected on at least four main elements of unprofessionalism: the delay of the Palembang PHO in implementing integrated HIV antenatal testing; the lack of coordination between the HIV programme and maternal and child health programmes; the heavy reliance on the health workers' personal judgement in offering HIV testing; and, lastly, the inadequate and limited HIV training for midwives. In the next section, I discuss how these four elements of unprofessionalism were presented in the HIV screening programme.

HIV screening is only being implemented for one year

Although the MoH Regulation (*Permenkes* number 51) in 2013 (MoH, 2013a) made the offering of HIV testing at antenatal clinics mandatory, this regulation was implemented at Palembang only in the beginning of 2017, four years after it was introduced as a national direction and policy. According to this regulation, every pregnant woman is mandated to be offered HIV testing at her antenatal care visit. Furthermore, HIV testing must be integrated within the minimum standard of health services or *standar pelayanan minimal* (SPM) in primary health settings, including *puskesmas* (MoH, 2016). Therefore, the successful implementation of HIV screening is now an important element in the programme evaluation of Palembang's health achievements.

Mandatory HIV screening was passed on as regulation within our PMTCT service in 2013. However in 2013, none of the VCT centre in *puskesmas*, ever reported any HIV test for pregnant women. This year, 2017, we feel more pressured to recommend an HIV test for pregnant women (Dr Lia, a medical doctor and HIV specialist).

After HIV testing was made a part of basic health services for all pregnant women, all 41 *puskesmas* in Palembang provided HIV testing, and 12 new VCT centres were established in *puskesmas* by the end of 2017. At the time of this study (early 2017), there were 16 VCT centres, mostly located in hospital-based settings, with only three in *puskesmas* settings. After July 2017, the Palembang PHO requested HIV testing tools for all *puskesmas* from the South Sumatra PHO. The South Sumatra PHO then requested HIV testing tools from the Indonesian MoH. The MoH is a hierarchical structure of government (central, provincial, and local) that undertakes procurement procedures related to HIV for most HIV programmes. The MoH also has a joint budget shared between the Indonesian government (*APBN-Anggaran Pendapatan dan Belanja Negara*: state expenditure and budget) and international donors (Global Fund) (see Chapter 3). Nevertheless, the implementation of HIV screening for all pregnant women still seems challenging due to the fragmented health system in Indonesia.

Officer 1: Our provincial PHO has a rapid test for HIV.... our obstacle is on the distribution of 100 rapid test to each *puskesmas*. We are not confident with the ability of the staff at the *puskesmas* level to administer the test.

Officer 2: Yes, we can.

Officer 1: Are you absolutely certain that your *puskesmas* staff can do it?

Officer 2: Yes, we can, the test is simple; we just prick the finger ('seekreek', the sound of pricking blood). If the result is positive, then our staff would refer the patient to the closest VCT centre.

(FGD with health programme officers and health professionals)

These narratives highlight the problem that within the complexity of fragmented bureaucracies in health systems in Indonesia, from the national level (*tingkat nasional*) to provincial (*tingkat provinsi*) and then district levels (*tingkat kota/kabupaten*), there is evidence of a challenge in performing quick response HIV screening in Palembang. The narrative also shows that a health worker may consider an HIV test as a simple test, in which all that is needed is to "just prick the finger", as a part of regular blood tests for all pregnant women. However, if HIV programmes do not accommodate the multilayered complex life experiences of being a HIV-positive woman, knowing HIV status during a pregnancy or after a delivery may become like a nightmare for an HIV-positive woman (see Nika, Ani, and Adel's stories in this chapter).

Inadequate and limited HIV training for midwives

In recounting Nika's story, the VCT team at the *puskesmas* level may not have understood the right of a patient to confidentiality after undertaking an HIV test. However, lack of HIV understandings among trained health workers in the VCT centre may halt knowledge transfer to untrained health workers for HIV programmes (e.g. Nika's midwives), about the urgency to respect patient confidentiality. Based on my observation, it is evident that there were a number of training sessions and coordination meetings in Palembang to support the implementation of PMTCT services, including patient confidentiality. Nevertheless, training and meetings were targeted for a VCT and Counselling Support and Testing (CST) team that consisted of a nurse, medical doctor, and laboratory technician; I observed only one training session that targeted midwives during my four-months fieldwork.

In June 2017, I was invited to attend an HIV workshop given to 40 midwives from all *puskesmas* in Palembang. The workshop was run for four hours to cover what the PMTCT service is, and the importance of HIV screening and the technical procedures for HIV-positive

pregnant patients. The training was run in a lecture mode; participants were sitting on a carpet, and the trainer stood at the front of the class. Participants were passive learners, and there was no opportunity to share ideas or experiences (Figure 6.1).

One of the trainers informally told the midwives that she was aware of the 100% HIV antenatal test coverage target, saying “we would all be feeling embarrassed if we could not achieve that 100% antenatal HIV coverage... it would be a shame to our Palembang Mayor”. Additionally, the discussion on patients’ privacy was based on scare tactics (*menakuti-nakuti*), rather than on an interactive discussion about patients’ rights and the consequences of breaching those rights. Therefore, the ineffectiveness of knowledge transfer within this training and the notion of being ‘target-oriented’ to protect the reputation of Palembang’s municipality may contribute to a lack of understanding about the importance of HIV testing for pregnant women.



Figure 6.1: Workshop for midwives on PMTCT and HIV screening at Palembang PHO, June 2017.

Relying on the subjective judgement of health workers

For a health worker to offer an HIV test to her patient is not easy. In a few cases, a health worker may order an HIV test without the patient’s knowledge (see Nika’s and Adel’s story in this chapter). A health worker’s decision to offer an HIV test to her patient might be influenced by her personal and subjective judgment and fears of rejection. Her fears of rejection may relate to fears of the risk of patients leaving, particularly in facility-based care such as public and

self-prevention mechanism, preventing them from getting infected with HIV.

“It is normal” to be fearful of HIV infection

Among healthcare workers (midwives, nurses, general practitioners, and specialists) in this study, anecdotes about fear were rife. While doctors and specialists might be said to have better knowledge of HIV than nurses or midwives, the opposite could also be said. According to Dr Zizi (a senior male obstetrician with 10 years’ experience helping HIV-infected pregnant women), the understanding about HIV among obstetricians was that HIV-positive patients were “... just like other people in general population” (Dr Zizi). In other words, doctors were also fearful of HIV infected people, even though they had medical training on universal precaution measures for treating HIV-patients as if they were ordinary people in the wider population. Unfortunately, fears of HIV-positive patients continue to be considered a widely accepted norm in a healthcare setting. Some argue that healthcare workers are only human beings and feeling fearful of being infected with HIV from a patient is normal. Healthcare workers have families to look after; so they do not want to risk contracting HIV.

Too many doctors still do not know about the principles of HIV transmission; therefore, their fear is excessive, that is normal, as I used to be like that in the past. After gaining some training, I now know that hepatitis is more infectious than HIV....
(Dr Lia, a female medical doctor, HIV specialist, FGD, May 2017)

Healthcare workers I encountered were adamant that their practice was non-discriminatory and non-judgmental. They often expressed anger towards me and felt that my findings related to discriminatory practices for HIV-positive women in health settings were accusatory: “why do you always blame us, healthcare workers?” However, an insider, who is a general practitioner, told me if a patient suffering from tuberculosis visited the *puskesmas*, his peers hid or avoided interaction with the patient. He added, “can you imagine if one HIV-positive patient visits *puskesmas*?” Other insiders observed the panic and trepidation in the surgery and operating theatre when they were presented with an HIV-positive patient, saying that the health workers were panicked (*kalang kabut*). Another saw a specialist use several layers of protective gloves to merely check a woman’s abdomen. One of my HIV-positive participants said that an obstetrician put a condom on a stick to check her unborn baby. I suggest inadequate knowledge related to HIV and fear of HIV-infected patients may contribute to avoidance of treating HIV-positive patients, including pregnant women with HIV.

p. iii). Thus, gendered morality creates unfairness for women within a dominant patriarchal Muslim society, particularly for HIV-positive married women (see Ayubi, 2015).

Women with HIV in Indonesia reported being negatively labelled, stereotyped, and receiving denigrating and discriminatory treatment when accessing HIV treatment such as PMTCT services, compared to men living with HIV (Butt, 2015; Hardon et al., 2009; Hidayana & Tenni, 2015; Imelda, 2014; Lazuardi, Bell, & Newman, 2018; Munro & McIntyre, 2015). In my study, women were all well aware of stigmatisation, fears, and prejudices present in healthcare services and they often had to deal with harassment and derogatory comments and treatment. Some women also depended on their husband's decision and support for their health. According to Noone and Stephens (2008), the patriarchal structure and male dominance over women has reinforced men's masculine identity as "virtuous users of health care services" (p. 711) and gender inequalities may contribute to a lack of women's access to PMTCT services. This gendered morality can result in a localised phenomenon, the stigmatisation of WLWH, and only recognises individual responsibility and is "away from broader structural conditions" (Mills, 2017, p. 318), such as gender norms and the status of women in a patriarchy. Hence, the bias of health systems, lack of privacy, and persistent victim-blaming attitudes may contribute to institutionalised discrimination in PMTCT services among women.

The current report highlights that gendered morality may reinforce the double standards of gender norms in society and may also intersect with other stereotypes affecting certain marginalised groups such as HIV-positive women. For example, a woman is expected to be obedient, but not man; a woman is expected to be monogamous in marriage, but not man; being obedient and faithful after marriage is expected only of the wives (see Chapter 2). The intersection of these gender elements may limit the ability of women, particularly those in a relationship (e.g., marriage), to negotiate their needs and acquire sufficient personal freedom to have their health needs met by making informed and independent decisions without their spouse's involvement, in relation to the use of PMTCT services.

The topic to be discussed is existing gendered morality, the power imbalance between healthcare providers and patients, and women's agency in accessing PMTCT services. This section comprises three parts: 1) The concern that 'it is hard to get permission from my husband'; 2) 'women are responsible for spreading HIV'; and 3) 'a need of women's space with trained midwives'.

revealed various dilemmas. He was required to undertake HIV testing without Lela's and Anti's husbands' permission, as per the regulation statement, but to do so, risked disagreements within his patients' marriages. His only alternative was to ask the husbands' permissions for their wives to undergo HIV testing, but he would not be able to treat his patients properly, if the husbands disallowed the test.

Anti came to the clinic with symptoms of yellow and white milky discharge. She had been treated by an intern physician for her STI and referred to Dr Didi for a follow up HIV test. Anti came to Dr Didi's practice with her husband. Dr Didi recalled seeing Anti looking very weak. Following an individual consultation for HIV, Dr Didi suggested that Anti have an HIV test. Anti's husband was very upset and insisted that "it was impossible for his wife to have HIV". Dr Didi explained to him that it was important to have the HIV test done to provide his wife with the right treatment. Anti's husband finally agreed for his wife to have the test. When the test results came back negative, her husband smirked at Dr Didi saying, "I told you so! It is not possible for my wife to get infected with HIV".

Dr Didi recalled a similar story. Lela asked Dr Didi for an HIV test as she was suspicious about her husband having extramarital relationships. She was also worried about her reproductive health as she had previously had three miscarriages. However, her husband did not permit Lela to undertake the HIV test. Lela's husband, a high-profile local parliament member, insisted, "never in my life... I am not badly behaved (*nakal*)".

Text-box 6.2: Anti and Lela: HIV testing procedures for married women and the dilemma about their implementation

In the two narratives of Anti and Lela, the women were aware of their reproductive health, yet remained powerless to take control of and exercise their right to good health. Their ability to make independent decisions was impeded by patriarchal values that meant married women were considered to be subordinates of their husbands; these values extended to practices within healthcare delivery systems. It is evident that rather than focusing on the health and needs of Anti and Lela, Dr Didi was hindered by these patriarchal values and worries over his career and reputation. As Dr Didi said to me, "I don't want to have any dispute with their husband later" (Didi).

Unequal rights affecting women's decisions around their own reproductive and sexual health

Men's support is key to women's reproductive health and the prevention of STIs and HIV transmission from mother to child. Both Anti and Lela were very courageous in seeking treatment and risking their good names (*nama baik*) and reputations for having STI treatment and HIV tests. However, both narratives reflect the inequality in decision-making power

professional and a policy maker. In their stories, there were dynamics of gendered power relations, with husbands having control over their wives' bodies and healthcare workers having limited agency or being powerless to offer HIV tests and inform patients about additional HIV testing for the next six months. Additionally, the morality issues associating HIV with sin, immorality, and unfaithfulness, combined with the narrow perspective that marriage protects against contracting STIs and HIV, limit opportunities for women and their husbands to access the appropriate treatment for their family health (Anindita & Shaluhyah, 2016; Butt, 2015; Jacubowski, 2008).

In summary, women's rights to access an HIV test are violated due to HIV and gender discrimination and institutionalised stigmas surrounding HIV evident in the Indonesian health setting, even amongst HIV specialists. In the narrative, there is evidence of a lack of decision-making by women for their own health within individual, family, community, and policy spheres (see Figure 6.2). The narratives of Anti and Lela show that the women were powerless to decide on their health, even after exposure to information about HIV and accessing health settings.

Unfortunately, being diagnosed with a STI, a risk factor indicating vulnerability to HIV, may limit women's rights to get independent informed assistance due to stigmatisation. STI diagnosis also limits health workers' ability to exercise their professionalism by providing information about the importance of HIV testing for both men and women, and initiating the same test for male partners, not just the females. This section has analysed the barriers for married women with STI and other reproductive health concerns, to accessing HIV testing, as the initial uptake of PMTCT services.

Adel's story: A woman is responsible for spreading HIV

Adel's story was retold by a midwife, Oci, working in a private maternal and children's hospital during an FGD with 11 other midwives. Adel is a young HIV-positive mother aged 20 years. In midwife Oci's story, about Adel and Tono (Text-box 6.3), the interplay within and between power, gender relations, and symbolic representations of gender in a heteronormative marriage, relationship, and health setting can be seen (Bottorff, Oliffe, Robinson, & Carey, 2011). In the narrative, Tono maintained his masculine identity, as a virtuous user of health care services, and his dignity was preserved as head of the family, presenting himself as a virtuous guide for his wife. He declined to undertake HIV testing and declared confidently in front of the health workers and his family that he was free from HIV. Nevertheless, after his wife's discharge, he

to take another HIV test, of engaging Tono to undertake an HIV test, and the opportunity to access ARV therapy for Adel and early prophylaxis therapy for her baby to prevent HIV after her delivery.

This narrative of Adel and Tono has demonstrated the barriers to accessing PMTCT services in relation to the intersection of cultural and gender discrimination around being an HIV-positive woman within wedlock. In religious and cultural terms, the man's role may be seen as providing moral guidance to protect his wife. However, it may have a negative health impact due to restricted rights and access to making informed and empowered choices regarding health services. This narrative also exemplifies gender discrimination in that a husband can be informed about his wife's HIV status, reject HIV testing, and bravely confess to being free of HIV without undertaking testing. However, the wife did not have any space for confidentiality, was inadequately informed of her rights, and pressured by moral judgements from female healthcare workers. Consequently, an HIV-positive woman may have limited ability to exercise her rights, obtain correct information about HIV and PMTCT services, have privacy, and be able to access PMTCT services. Violation of women's rights, however, may put a woman and her infant's life at risk. The following story offers another perspective on accessing PMTCT services by an HIV-positive pregnant woman with well-trained health workers to HIV programmes.

Lilis' story: A woman's space with a trained midwife in antenatal care services in puskesmas

During a go-along interview, Dr Ina recalled seeing a pregnant Lili coming to the *puskesmas*, with "an itchiness in her anus". Fortunately, the midwife in the *puskesmas* had been exposed to HIV training and was confident enough to ask some sensitive questions of Lili: "*Bu* [madam] have you ever had an anal sex?" Lili: "yes, my husband asked me to do so". At that point, the midwife decided to take a swab from Lili's anus to check for infection. In this case, the midwife was able to use the right question to determine the risk of Lili being infected with HIV. Dr Ina acknowledged it would be very challenging for any healthcare worker who had never been exposed to HIV training to ask such taboo or personal questions of their patients, as did the midwife in her *puskesmas*. She pointed out that even as a general practitioner, she doubted she would feel comfortable asking such questions: "can you imagine at a midwife level asking these sensitive questions in an Indonesian context?" (Dr Ina)

Text-box 6.4:Lili's story: Anal sex with her husband

additional factors that may contribute to multiple missed opportunities for early PMTCT of HIV. The second section revealed how the interplay of health systems, information, and economic barriers, for example, self-stigmatisation, endless referral procedures, and normalisation of fears of treating HIV patients in health settings, may prevent a woman from exercising her rights for the sake of her health and to have a child free from HIV. Lastly, considering gendered morality and institutionalised discrimination, additional gendered cultural barriers may prevent married women at risk of or with HIV from accessing comprehensive PMTCT services. Factors include the non-objective treatment of married women, failure to offer HIV testing to male partners, the right for women to make decisions about their reproductive health, and narrow perspectives of married spouses at low risk of HIV transmission.

Cultural barriers, as well as health system, information, and economic barriers, must be recognised as an important factor in obstructing access to PMTCT services, that lead to mistrust between female patients and health care professionals (Figure 6.2). Unfortunately, women may not be aware that they are being discriminated and perpetuate the cultural norms that violate their rights to informed choice, access to prevention and treatment services, and the opportunity to bear a healthy HIV free baby. Therefore, improving access to PMTCT services in Indonesia should consider the constraints of gender morality within social, cultural, and political norms, and address the multifaceted barriers to accessing HIV testing and seeking comprehensive PMTCT service for women and their babies.

This current study reveals the complexity of HIV vulnerability and transmission among married women within and outside of marriage. Topics for knowledge sharing include: notions of shame to talk about HIV, values of marriage and motherhood, the low rate of condom use, non-disclosure of HIV status and homosexual orientation, economic dependency to one's husband. Others topics related to health services are silence surrounding HIV in society and health settings, institutionalised stigma and gendered discrimination among health workers and society within non-integrated health systems, and poor HIV screening among women, including those who are pregnant.

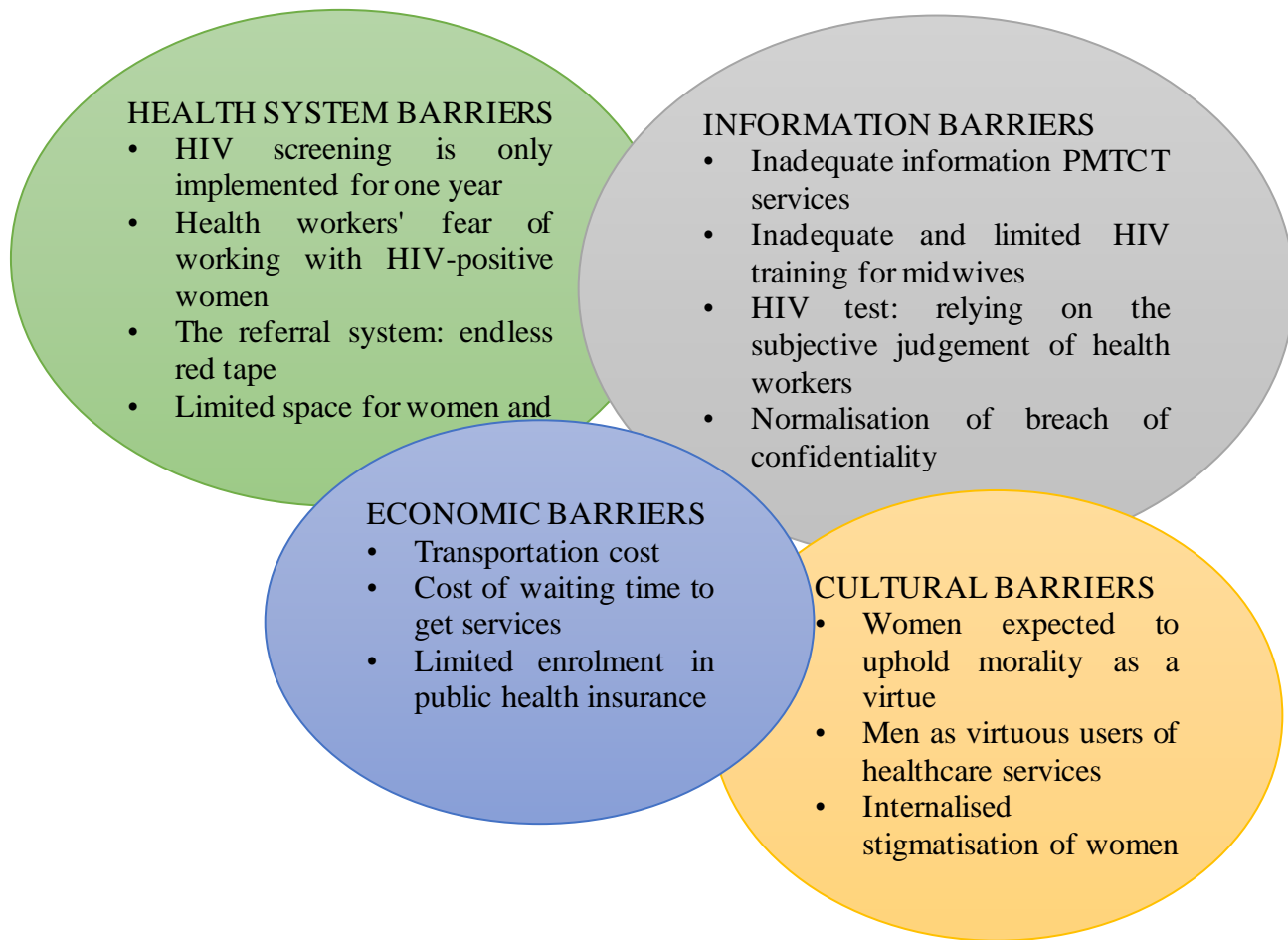


Figure 6.2: Barriers to accessing PMTCT services

Thus, within a patriarchal culture, where a husband has dominance over his wife's reproductive health, and where a wife should obey her husband, women need to be informed about the risk factors of HIV transmission. Women need to be empowered to make responsible decisions in their own right to understand HIV transmission and reduce contracting and transmitting of HIV. Finally, in order to reduce the risk of mothers contracting HIV and transmitting this to their children, and to enhance women's early access to PMTCT services, service providers need to be aware of, and address these gender discriminatory factors in their training and policies.

1. Introduction

As discussed in Chapter 6, accessing PMTCT services is complex. As long as barriers to accessing PMTCT services exist, women cannot prevent transmission of HIV to their children. This chapter analyses ways to provide HIV-positive women with access to PMTCT services. Discussions with 18 HIV-positive women provided the main data for this chapter. During these discussions, the women and I explored various strategies for them to better access PMTCT services: creative media such as poems, drama, puppet shows, mind-maps, drawings, and videos were produced by the women. For example, one of the creative outcomes used in the prologue of this chapter, was a traditional song with modified lyrics expressing their thoughts on the importance of antenatal HIV testing at midwifery level (as discussed in section 3 of this chapter). The data from these discussions has become a tool through which I can visually and verbally advocate for these women to be able to access HIV care services, especially PMTCT services. The shared discussions empowered the women to demand better access to health care from other groups in this study. Further suggestions, added by groups of NGO workers and healthcare professionals, provide detailed mechanisms to enable women to access PMTCT services.

This chapter includes five sections. The first section pertains to what women need to access PMTCT services within the individual sphere, and the second section addresses factors within the family sphere. The third section includes factors within women's social or community sphere, and the fourth section concerns supporting factors within public spheres such as public policy and gender norms. These four spheres are interlinked and it is argued that there is a need to address the overlapping spheres to enable women to access PMTCT services (Najmah, 2018). Thus, missed opportunities for early diagnosis and treatment of HIV-positive [pregnant] mothers may be prevented, eliminating perinatal HIV transmission and ensuring women and children who have been diagnosed with HIV will get proper treatment.

2. Individual sphere: What women need to access PMTCT services

Within this sphere, the focus is on developing women's personal skill-sets in ways that increase their confidence to access relevant and timely information and resources regarding HIV. All of the HIV-positive women critically reflected on their experiences only when they knew about their HIV; that too, was at a very late stage. Thus, women should improve their health literacy to enable themselves to access HIV care and engage their husbands to visit PMTCT services.

Zee, her daughter who was seven years old at the time of this study and was HIV negative. In her poem, Mona wrote “enough to wipe off my tears, sing a cheerful song” (*hapuskan tangisku, bernyanyilah ceria*), and at the end of her poem she expressed her hope and love for Zee to “keep on living and embrace your ambition” (*Melangkahlah terus gapai mimpimu*). For Mona, Zee provided the main motivation to survive after her first husband passed away due to AIDS related diseases. Mona’s love for Zee was reflected in her agency to access ARV therapy for her health, and pursue her university studies to become financially independent by working for a company. In line with her poem, Mona also showed me Zee’s picture that depicted a mother goose feeding her three goslings (Figure 7.1). In Mona’s imagination, the drawing reflected Zee’s dreams to have her mother (Mona) looking after and feeding three children. At the time of the drawing, Zee was Mona’s only child. Later, in 2015, she decided to remarry and give Zee a ‘normal’ family and siblings.



Figure 7.1: Zee’s drawing of a mother goose and her goslings (Najmah, 2019, 23 August)

Most of the HIV-positive women in this study came out of the dark without anticipation. Like Mona, other HIV-positive women in this study needed to navigate their own HIV status, strive for their children, and if possible, pursue their dream of having of a ‘normal’ family in order to continue their life. In Mona’s story, I highlight three main elements to being resilient and resourceful: self-reliance, emotional strength, and the independence to make choices. I now turn to the second element that women need to access PMTCT services—knowledge.

for an HIV-positive wife, commitment to enjoy a family life together, despite his wife’s HIV status, and commitment to support his wife to adhere to ARV therapy. Both of them also accessed PMTCT services in 2017 for planning their second child, Zee’s brother. They chose to use condoms as their contraceptive method, to keep their family healthy.



Figure 7.3: Mona’s poster: I am HIV positive



Figure 7.4: Adi’s drawing entitled ‘Living to the full’

From Adi and Mona’s narrative and drawings, I learned the importance of encouraging HIV-positive women to disclose their status to their partner. I am aware that being HIV-positive will not prevent women getting pregnant; thus, disclosure of HIV status is necessary for them to access PMTCT services. As evident from Mona and Adi’s story, initially it was not easy for Mona to disclose her HIV status and for Adi to accept Mona after her disclosure. Nevertheless,

protection from contracting HIV, while HIV-positive women need a safe physical environment and communicative space to deal with their HIV and to access PMTCT services. My participants said that knowing their own HIV status at a late stage, after their husband's and child's sickness, was unacceptable. Thus, supportive environments within the health services were key to their health.

4. What health workers need to do to enable women to access PMTCT services

Among healthcare providers who utilise a passive approach, that is, those who merely wait for patients to access HIV care, the attendance of an HIV-positive woman at PMTCT services should be considered a great achievement, and a reflection of the patient's bravery to fight her own internalised self-stigmatisation related to HIV. Therefore, a supportive environment within health settings is urgently needed for HIV-positive female patients to access PMTCT services. According to Brawner (2014), "neighbourhood social order and safety" is considered "a proxy for community-level involvement in health-related issues" (p. 637). This section takes the form of: 1) the reflection of one HIV-positive woman and child in a health setting, and 2) strategies to solve institutionalised discrimination in health setting. The discussion is based on perspectives, reflections, and creative outcomes from an HIV-positive mother, two groups of HIV-positive women, two groups of NGO workers, and health workers (midwives and a senior obstetrician).

A reflection of a lived experience of an HIV-positive woman with a child

This section recounts what HIV women want from health care providers. I chose Oda's story to best describe the types of supportive, non-discriminatory environments that women aspired to have within existing HIV services. Earlier, I included Oda's story relating to support from her husband and mother-in-law. Oda recalled that the breach of confidentiality during her and Malin's treatment was unacceptable and a very poor practice by the health clinic. One time, when visiting the hospital, one of the doctors loudly asked her about "where is ARV drugs for Malin?" (Oda), which was heard by other clinic visitors ("*mana obat HIVnya*", *dokter bertanya disaat ada tamu Ibu Oda di ruang rawat inap*). She also recalled being discriminated against when Malin was transferred from an in-patient room to an isolation room after being diagnosed with HIV.

in areas classed as having a low HIV epidemic. Thus, there was a particular focus on peer education schemes amongst health workers and mentorship between senior and junior staff, and between trained and untrained health workers related to HIV, as well as training in interpersonal and counselling skills when working with HIV-positive patients and their families (face-to-face), and peer education through an online platform. Building partnerships with health organisations and providing confidential telephone support is also urgently needed to support the implementation of HIV programmes in health settings and PHO in Palembang.

Peer education for interpersonal skills

The first strategy aspired to by participants was face-to-face peer education, or communication between the HIV specialist and health workers with poor understandings of HIV. Healthcare professionals should have the ability to provide psychological and emotional support for women and families, especially when delivering news about HIV and treatment plans for newly HIV-infected pregnant women. The role play depicted below (Figure 7.7) exemplifies the effectiveness of face-to-face peer education related interpersonal skills in treating HIV patients by a senior HIV specialist health workers, for midwives and nurses without formal HIV training. In the role play, the doctor first listens to the health workers' concerns about treating HIV patients, then he/she clarifies misconceptions around HIV and encourages other health workers to seek further information through an online platform. At the same time, the doctor exemplifies non-discriminatory behaviour in treating HIV-positive patients (Appendix D.b).

Scene 5

In scene 5, once the doctor arrives and hears Intan's complaints, he calls the duty nurse responsible for Intan. The doctor listens to the explanation from the nurse and educates her with correct information on HIV transmission. The doctor then instructs the nurse to search (for) current information about HIV and about professional conduct of staff working with HIV patients on the Internet using her mobile phone, and to learn about the rights of HIV patients to receive equal and quality, non-discriminatory treatment.

In the next few days, Intan notices markedly different treatment from the nurses, as they are kinder and friendlier. Intan also receives clear information about appropriate contraceptive methods for HIV-positive couples to prevent unintended pregnancies and provide prophylaxis treatment for her baby. The story ends with Intan, her husband, and baby going home.

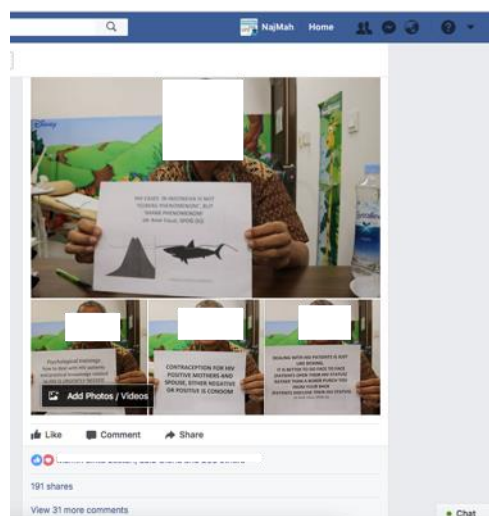
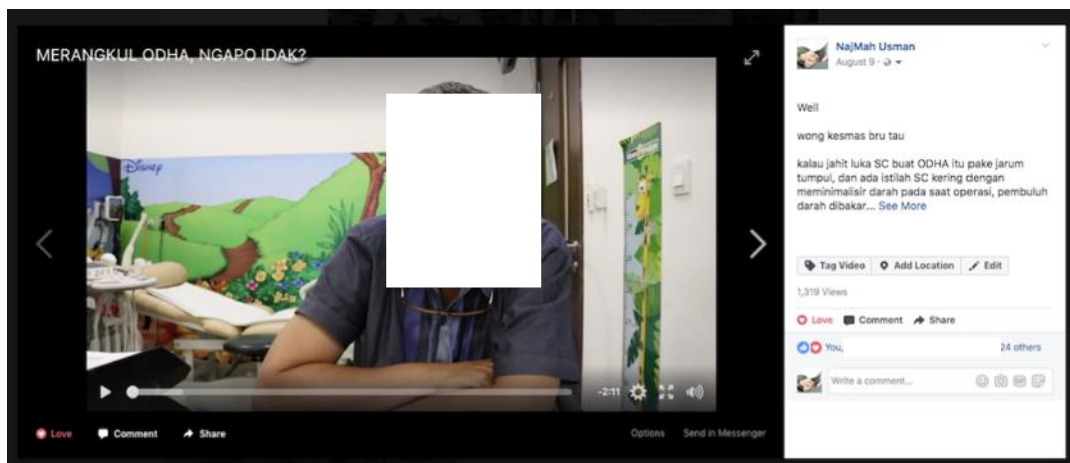
Text-box 7.1: Scene 5: Role Play by Sehati B (a group of six HIV-positive women)

Online peer education

The second strategy suggested by health worker participants was peer education through an online platform. Zizi, an obstetrician with a decade of helping pregnant WLWH in Palembang,

this video to my Facebook account (August 2017), it received 1,319 views, and 200 people (mostly health workers) shared the video (Figure 7.7). Upon analysing over 50 comments on this video, there were many positive comments, like “feeling great to be his client”, “very inspired doctor”, “the best doctor”, and “kind-hearted doctor”. These comments challenge the common assumptions that health workers working with HIV-positive clients, are likely to lose their HIV-negative clients, due to the social stigma attached with HIV. One of the comments from a health worker in this video on my Facebook:

My big appreciation (*salut*) was for him. Most health workers avoided treating HIV clients, but he was kind, friendly, and provided a comfortable space for us during the consultation. He helped HIV-positive mothers to deliver healthy babies. When I worked in a private hospital with him, he reported to the centre of infectious disease control when the needle that was used for his HIV client, accidentally hurt him during the operation. Fortunately, he was not infected with HIV. God protects good people. (A female health worker, August 2017)



group was also interested in giving confidential and constructive feedback to services for future improvements to create supportive environments in health settings. Generally, HIV-positive women were afraid to make a complaint, perceiving that it may be counterproductive and result in their being denied services at the clinic. Some women (e.g. Mira) reflected on their experiences of trauma, emotional pressure, and fears of transmitting HIV to their children, while simultaneously dealing with institutionalised discrimination when accessing comprehensive PMTCT services during their pregnancy (see Chapter 4: Mira's story). Healthcare professionals, without hearing directly from their patients, would assume that HIV patients would have been satisfied with the services provided. Thus, the strategy should focus on services and policies that protect women's rights to non-discriminatory services by providing confidential phone lines for constructive feedback to enable women to exercise their rights in health settings. The description by Intan in Text-box 7.1 is an example of the bravery of an HIV-positive woman to make a complaint. A good, quick response by health workers to address her complaint contributed to a supportive environment during treatment (see Text-box 7.4, below).

Scene 4

Scene 4 relates to post-delivery when Intan and her baby are transferred to the maternity ward. Intan feels relieved that her baby is delivered safely by caesarean section. However, she is still very upset by the discriminatory treatment and bullying she received from the admission nurses prior to the arrival of the PMTCT team. Fortunately, she chooses to exercise her right to fair treatment for HIV-positive clients and calls a doctor in the VCT centre to complain about the discrimination.

The following dialogue is an extract from Scene 4, when Intan was in the maternity ward post-delivery.

Ring ring ring The patient phones a doctor in the VCT centre (sounds of a phone ringing)

Intan Hello

Doctor Yes

Intan Hello doctor, oh my God (Ya Allah), please help me, doctor, I was asked to provide my own plastic cover for my baby's bed sheet and I cannot use the hospital one. I feel very upset, please help me, doctor. I felt discriminated (terkucil), I was cornered (cak tersudut) in this hospital. Oh, my God, I feel so disappointed to come to this hospital, please help me, doctor.

Doctor Be patient. I will come and see you as soon as I can. I am currently still with another patient, but I will be there soon.

Intan Yes, doctor, please help me. (Then a doctor came to see Intan in her room in maternity ward room (Background music playing.)

Text-box 7.4: Scene 4: Role Play by Sehati B

we don't even obtain information related to HIV?" (NGO workers, May 2017). This quote from a traditional poem depicts the current situation of poor knowledge at grass-roots level regarding HIV among (married) women (Text-box 7.5).

First verse

Mrs Ani buys some tomatoes
 Tomatoes for making the soup....
 How can we (be) healthier
 If we don't even obtain information about HIV

Second verse

Build a house with lots of walls
 Having some avocado smoothies during our break
 C'mon empower our information centre for community health
 So mothers and babies are healthy and HIV free

Text-box 7.5: Modified poems with theme of “Communication, information, and education” by five NGO workers

(See Appendix D.a.5 for Indonesian version).



Figure 7.8: HIV posters inside VCT rooms in two hospitals in Palembang

Note: Copyright (2014) by MoH and PHO.

Note: Poster 1 is about HIV testing through VCT online, Poster 2 is about accessing HIV testing and ARV therapy for me and my baby, and Poster 3 is about avoiding HIV -AIDS by being faithful to family

From my observations, it seemed that posters about HIV were mostly located inside VCT rooms (separated by an antenatal care room), and do not use simple language, but instead use medical terms (see Figure 7.8). Messages for health prevention of HIV also focus on moral judgement messages, such as that being faithful is a way to avoid HIV transmission (Figure 7.8, Poster 3), or negative messages, such as HIV and AIDS are deathly diseases. Thus, a key

principle for the promotion of HIV testing must be to use simple language for low-risk groups with less moral judgment, particularly for *ibu rumah tangga*.

Participants believed that relevant and up-to-date information on HIV should be available, accessible, and visible to women in antenatal care clinics and health settings, using the local (Palembang) language. For example HIV testing should be called “*tes imunitas untuk ibu dan anak*” (immunity test for mother and child) (FGD with HIV-positive mothers, May 2017). Other proposed messages were “*Mari selamatkan ibu, anak dan tenaga kesehatan dari HIV*” (let’s protect mothers, children, and health workers from HIV, see Figure 7.9) and “*Payo mangcek bicek sanak sedulur, ajak keluarga perikso HIV untuk kesehatan bersama di Puskesmas/Rumah Sakit terdekat!!*” (Uncle, aunty, and other family, please engage your family to undergo HIV test for our health in the closest puskesmas/hospital!!, see Figure 7.10) The messages should reflect that offering and undertaking HIV testing to patients means preventing passing HIV to a future generation, and protecting health workers from contracting HIV. Further, effective communication and education or *KIE (Komunikasi, Informasi, dan Edukasi)* related to HIV and PMTCT services should be implemented with advocacy by women’s organisations (e.g. PKK⁶⁸), female cadres in *posyandu*⁶⁹, and midwives.

⁶⁸ PKK is the abbreviation for *Pembinaan Kesejahteraan Keluarga* (The Indonesian Family Welfare Guidance Programme or Family Welfare Movement), a state corporate organisation for wives of state servants (see Chapter 3).

⁶⁹ *Posyandu* is the abbreviation for *Pos Pelayanan Terpadu* (Integrated Service Post), which originally functioned as family planning and health services at grassroots level.



Figure 7.9: Simple language for PMTCT services: “Let’s protect mothers, children and health workers from HIV”

Note: These messages were designed by groups of HIV-positive women, health workers and NGO workers, and the design of the poster was by a research facilitator.

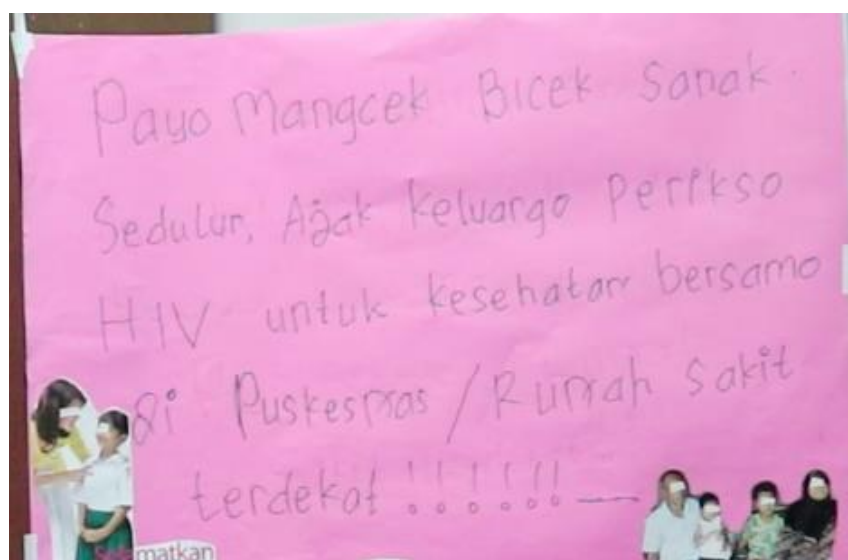


Figure 7.10: Health Promotion poster by Sehati A (six HIV-positive women)

Translation: Uncle, Aunty, and other family, please engage your family to undergo HIV test for our health in the closest puskesmas/hospital!!

Woman's space for confidentiality and privacy

PMTCT services should ensure the respect and protection of women's rights to privacy, confidentiality, non-discriminatory, and relevant health services. In the *Cuk Ma Ilang* Lyrics, HIV-positive women expressed the challenges for women undergoing HIV testing by saying "Hey mom, I am not afraid of HIV test, but to ask for my partner is not as easy as you said" (HIV-positive women, April 2017). Thus, taking account of the need for compulsory HIV testing, a further strategy to enable women to access HIV care should address gender equality. Participants believed that a woman should be able to make an independent decision regarding her health and treatment without asking her husband's permission.

HIV testing should be compulsory for all members of a family when a woman is found to be HIV positive. A married woman is not responsible for spreading HIV when she does not know of the potential for HIV transmission from her husband. HIV-positive women found that it was very difficult for a woman to get a full confession from their partner/husband about his past sexual practice or the use of injectable drugs. Thus, they believed that HIV testing should be compulsory for all pregnant women who access any type of health settings, from private midwifery practice, *puskemas*, maternity clinic, to hospital, ensuring the respect of women's privacy and confidentiality.

Shorter referral procedures

Access to PMTCT services is bureaucratic and frustrating. HIV-positive women, as well as peer support workers who accompanied pregnant HIV-positive women, expressed their unhappiness with the difficult and seemingly endless referral procedures, stating "I am confused, I am sad, I am scared, what should I do?" (NGO workers, May 2017; see Text-box 7.6). Hence, the group was adamant about the need for strengthening communication and teamwork of relevant services related to PMTCT services. If health workers were not able to monitor a newly HIV pregnant woman to access PMTCT services, peer support workers believed that there should be an integrated referral system so HIV-positive women could be referred to NGO workers to minimise missed opportunities and streamline the process of the PMTCT referral system in tertiary hospitals.

WHAT WOMEN NEED TO ENHANCE THEIR ACCESS TO PMTCT SERVICES

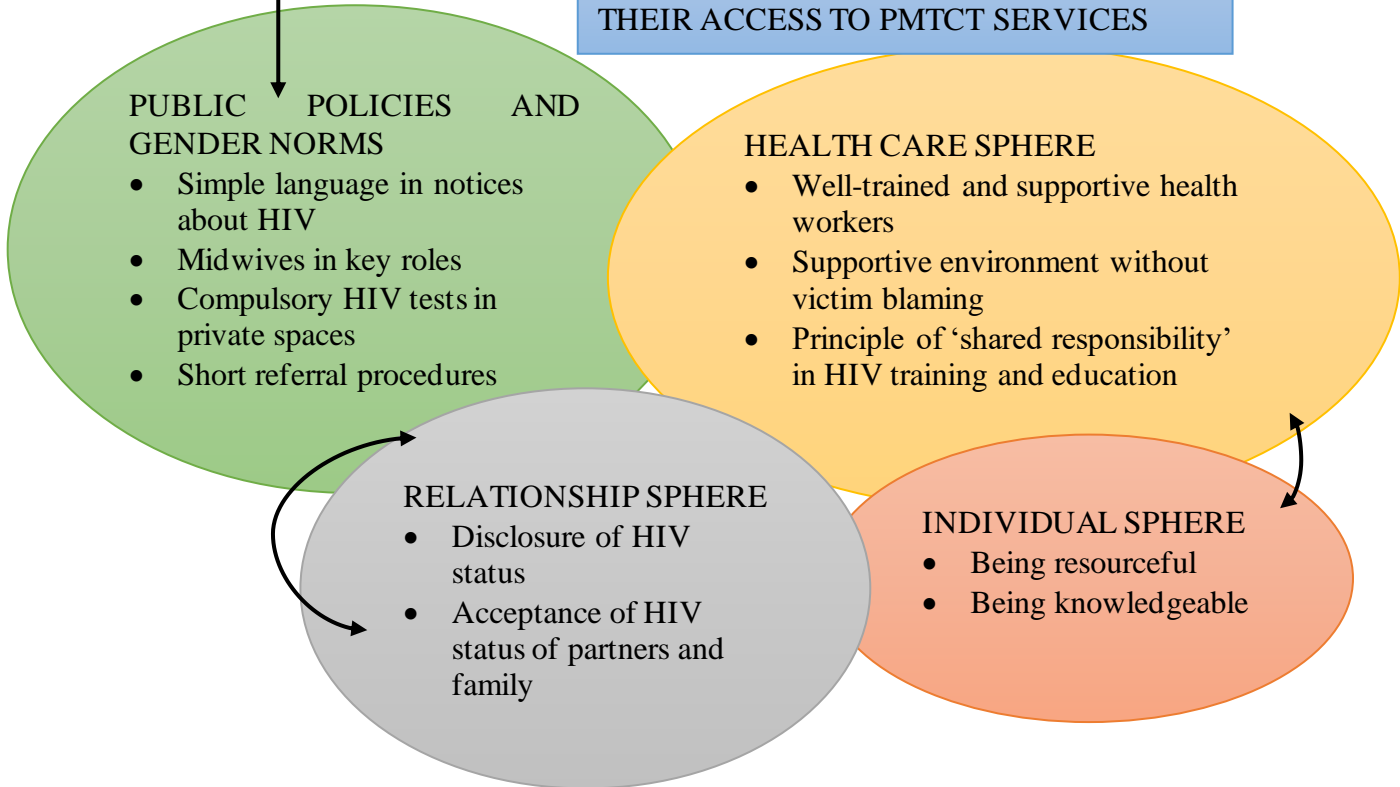


Figure 7.11: Four spheres of the elements needed to support women's rights to access PMTCT services

Chapter 8. Discussion

Becoming an *ibu rumah tangga* (a wife and mother) is something aspired to by the majority of women in Indonesia. The difficulty with idealising this position, though, is that *ibu rumah tangga* are always and only imagined to be faithful wives and doting mothers (Najmah, Davies & Andajani, 2020). Given their assumed “angelic nature” (a concept constructed and nurtured through culture and religion), *ibu rumah tangga*, according to Najmah, et al. (2020) are unproblematically considered “immune from diseases such as HIV, which are thought to affect only the immoral” (para.2). Additionally, negative attitudes and misconceptions about the transmission of HIV may hinder women’s ability to seek information on HIV prevention and to advocate for PMTCT treatment. However, statistics strongly indicate that unsafe heterosexual and homosexual practice may drive the increase of HIV among women in Indonesia. Further, *Ibu rumah tangga* may not know their HIV status until after their husbands’ or children’s sickness or death (Imelda, 2014; MoH, 2018; Rahmalia et al., 2015; WHO, 2016). Efforts are urgently required to improve early prevention and diagnosis of HIV among women, and to encourage HIV-positive women to access healthcare to reduce the risk of mother-to-child transmission of HIV.

The three last chapters (Chapter 5, 6, and 7) presented and analysed field data and provided empirical evidence of this study: who are the participants; how their positioning and experiences shaped their vulnerability; an in-depth analysis of barriers affecting women’s access to PMTCT services; and strong evidence-based conclusions of four interrelated spheres of the individual, the family, health workers and the government spheres on what women need to access PMTCT. This chapter offers three theoretical contributions that are relevant for public health work on HIV, women, and sexuality studies in Indonesia. The first is the conceptualisation of marital deception that contributes to women’s vulnerability to HIV. The second concept is the intersectionality of women’s vulnerability to HIV. The third concept is the intersection of stigma related to HIV, and how stigma is manifested across different actors and systems within Indonesian healthcare. Translation of research findings to action and recommendations for policy/programme makers will be discussed in Chapter nine. This chapter will now turn to examine the concept of marital deception.

1. The conceptualisation of ‘marital deception’ and HIV vulnerability in women

Marital deception increases women’s vulnerability to HIV. Marital deception is a complex phenomenon involving different spheres of women’s social life, interpersonal, and family. It may root in the social construction of gender norms and the state ideology in the Indonesian context. Marital deception refers to any acts of deceiving or when betrayal, deceit, dishonesty, and manipulation happens in a marriage (Merriam-webster, 2020).

Marital deception involves a wider sphere of women’s individual, interpersonal, and social environment. Within a woman’s interpersonal and family spheres, deception may be carried out by a woman’s partner and in-laws. At a wider sphere, deception is also indirectly reinforced by the culture of ‘fear of shame’ (*takut malu*) and ‘saving face’ (*jaga muka*) (Davies, 2015; Hirsch et al., 2009). These cultures also have been institutionalised by health workers’ attitudes and believed which are normalised within 1) the current health system, including regulations in Indonesia, 2) the marital continuum and 3) non-heterosexual practice, that will be further discussed on this section.

Most importantly, marital deception in Indonesia is socially constructed when social expectations placed on men and women differ in terms of their sexuality and sexual behaviour, such as the application of double sexual standards for men and women. The state gender ideology in Indonesia endorses the ‘heterosexual norm’ and an idealisation of heterosexual relationships and heterosexual marriage (Suryakusuma, 2011). Any practice outside this heterosexual framework is considered as ‘abnormal’ or ‘delinquent’ or ‘deviant’; sinful, ‘social illness’ or immoral (Andajani, et al., 2015; McNally & Grierson, 2015; Pisani, 2010). I observed there are types of sexual deception in this study, including bisexuality, homosexuality, extra-marital sexual relationships, and engagement with commercial sex workers and polygamous marriage (Andajani et al., 2015; Hirsch et al., 2009; Nurmila & Bennett, 2015)⁷⁰. These practices are hidden and may contribute to vulnerability to HIV infections among married women in Indonesia.

⁷⁰ Homosexuality, although it is not regarded as a crime, is publicly seen as a ‘social illness’ and immoral behaviour. Community and police force are enforcing a strict surveillance against practice of homosexuality, for example, during the holy months of Ramadhan by raiding hotels, boarding homes and pubs and clubs (Andajani et al, 2015).

Marital deception within a marital continuum

A marital continuum is to changes in a woman's marital status within her adult life span (Platt, 2017). According to Maria Platt (2017), the marital continuum refers to the fluidity of marital practices across a span of women's marital status in Indonesia, such as the fluidity of changes single, married, separated or divorced and widowed. A woman's marital continuum is specific to the individual woman's experiences. In my study, marital deception may happen in different points of her marital continuum of an HIV-positive woman and is also observed within a woman's marital span.

The conceptualisation of the marital continuum allows us to better understand the possible pathway of women's vulnerability to HIV and HIV transmission in heterosexual relationships. For example, in Chapter 5, Mawar's marital continuum included being single, first marriage, divorcee, and second marriage. Mawar was a former IDU and found out about her HIV status after she got divorced from her first husband. She hid her HIV status from her second sexual partner (second husband), and continued to practice unsafe sex. Her second husband also hid his polygamous relationship. In this example, both Mawar, her first and second husband actively practiced marital deceptions, which increase risk of HIV transmission to all sexual partners surrounding Mawar and her husbands. This research reveals that every HIV-positive woman in this study had their unique HIV vulnerability and marital deception, including the three stories from Mona (Chapter 1), Oneng and Mira (Chapter 5).

Marital deception in a non-heterosexual relationship

As noted earlier, homosexuality and bisexuality are considered sinful and immoral in normative Indonesian discourse. Social stigma and feeling ashamed are well observed amongst MSM communities in Indonesia. Generally, Indonesian people are not comfortable discussing homosexuality. Therefore, in PMTCT services, an HIV positive woman is vulnerable to 'victim-blaming' and often left alone to feel ashamed of her status. The health services are afraid to further investigate the pathway of HIV infection, and if any health workers were able to investigate risk factors of HIV within a spouse, the health workers and husbands may be afraid to share sexual histories of both parties (spouses). This imposes miss-opportunity for married spouses to access a comprehensive effort to prevent HIV transmission, in other key populations. I concur with studies of Andajani et al. (2015), McNally and Grierson (2015), and Pisani (2010) that homosexuality in Indonesia creates a silent mode of HIV transmission within a marriage, through unsafe homosexual practices. Future studies need to look into HIV and

2. Intersectionality and Women's Vulnerability to HIV

HIV transmission in women is complex. Hence, analysis of multi-dimensional elements within women's experience is required to be able to understand and explain the complexity of their lives and their situation, as related to their vulnerability to HIV (Bowleg, 2012; Maguire, 1996; Ponc, et al., 2010; Reid & Frisby, 2008). Women, according to Reid and Frisby (2008), are individuals existing at the intersection of multiple identities, all of which influence one another and together shape their continually changing experience and interactions. Therefore, the most common axes of disadvantage, when theorising HIV vulnerability from an intersectional paradigm, typically included women's HIV vulnerability in low-and middle-income countries, in Muslim and in Asian countries.

One of the most interesting findings in this thesis was that in Indonesia women are vulnerable to HIV transmission regardless of their socio-economic status (education, employment, income). Women's marital status does not protect them from the practice of marital deception. Complex intersections in a woman's life mean that, each of the 18 HIV positive women in this study had different elements that contributed to each woman's vulnerabilities to HIV infections. Each of their stories represents different intersections and pathways that determine their vulnerability. A woman may stand within the continuum of education, socio-economic status, marital status.

Manifestation of intersectional women's vulnerability to HIV, among married HIV-positive women, operated at multifaceted elements: 1) women's economic dependency on husband's income, 2) education level and HIV literacy, 3) women's marital status and HIV non-disclosure and 4) the notion of motherhood. Women with multiple intersections of unprivileged elements may contribute to a cumulative effect on women's vulnerability (Baral, et al., 2013; Brawner, 2015; Higgins, et al., 2010; Lin et al., 2007; Ostrach & Singer, 2017). HIV-related stigma (which will be discussed in the third section of this chapter) exacerbates women's unwillingness and inability to access HIV testing and to determine if they want to access (or not) PMTCT services. In Indonesia, with rates of new HIV infection among women of childbearing age, and their high rate of late stage, I argue that that deepening understanding of the intersectionality of women's vulnerability to HIV is required, particularly among married women to increase the access of PMTCT services.

may contribute to women's vulnerability to HIV. It may result in increasing mortality risk due to opportunistic infection related to Aids (see Mano's story in next third section of this chapter). Unfortunately, health workers may also be less likely to provide adequate information about the HIV status of the women with low-level education, from a poor family and to a widow or divorcee (Gourlay et al., 2013; Nguyen et al., 2009; Sangaramoorthy et al., 2017).

In summary, inadequate access to information, poverty, an outsider status of an ideal marriage, and lack of a husband's support may be also related to higher vulnerability to HIV infection among women. These intersectional elements prevent women from making informed choices to access HIV tests and then access ARV therapy in the early stage (Badriah et al., 2018; Hampanda, 2012; Hlartaithe et al., 2014; Samuels, 2018; Sangaramoorthy, et al., 2017). The result of this intersection supports the idea that without universal health insurance such as registering *BPJS*, poor women with less educated are left to decide how to afford PMTCT services compared to women from middle- and high-income women with well-educated (Demartoto et al., 2016).

Women's marital status and HIV's disclosure

Non disclosure of HIV status occurs within a marriage (Anindita & Shaluhayah, 2016; Butt, et al., 2017; Hidayana & Tenni, 2015; Hollen, 2007; Liamputtong & Haritavorn, 2014). Women's marital status is not a proxy for their vulnerability to HIV. Yet, partners' support, safe sex practice and consensual sexual practices, and honesty in marriage and early disclosure of HIV status of the individual affected, are the key to woman's and her family's HIV survival. However, not all HIV-positive women may disclose their HIV status to their husband, or vice versa after accessing HIV tests, prior to their marriage or during their marriage (Anindita & Shaluhayah, 2016; Badriah et al., 2018; Hidayana & Tenni, 2015). Hence, lack of a HIV partner notification could be one protecting factor on women's HIV vulnerability.

A HIV partner notification is "a means of identifying persons exposed to HIV who may be unaware of their exposure, and who may welcome notification and the opportunity to test for HIV" (WHO, 2016, p. 13). The current regulation of MoH, *Permenkes* no 52 in 2017, woman's agency is required to engage her partner/husband to get HIV, syphilis and Hepatitis B testing, and there is no regulation for HIV partner notification (MoH, 2017). With double standard gender norms in Indonesia and other Asian-African countries, women may choose to maintain their marriage bond by non-disclosure of their HIV status to their husbands or vice versa (Anindita & Shaluhayah, 2016; Hampanda, 2012; Hollen, 2007; Liamputtong & Niphattra

Participants explained their resilience to deal with self-stigmatisation and stigmatisation of HIV was driven by their determination to protect their children from HIV. These results corroborate with the findings of a great deal of the previous research on women, HIV, and motherhood in the Asian context. Notion of motherhood is as the foundation of women’s lives and the main motivation for survival and decisions around accessing HIV care in India, Thailand and Indonesia (Hardon, et al., 2009; Hidayana & Tenni, 2015; Hollen, 2007; Pranee Liamputtong & N. Haritavorn, 2014; Lumbantoruan et al., 2018).

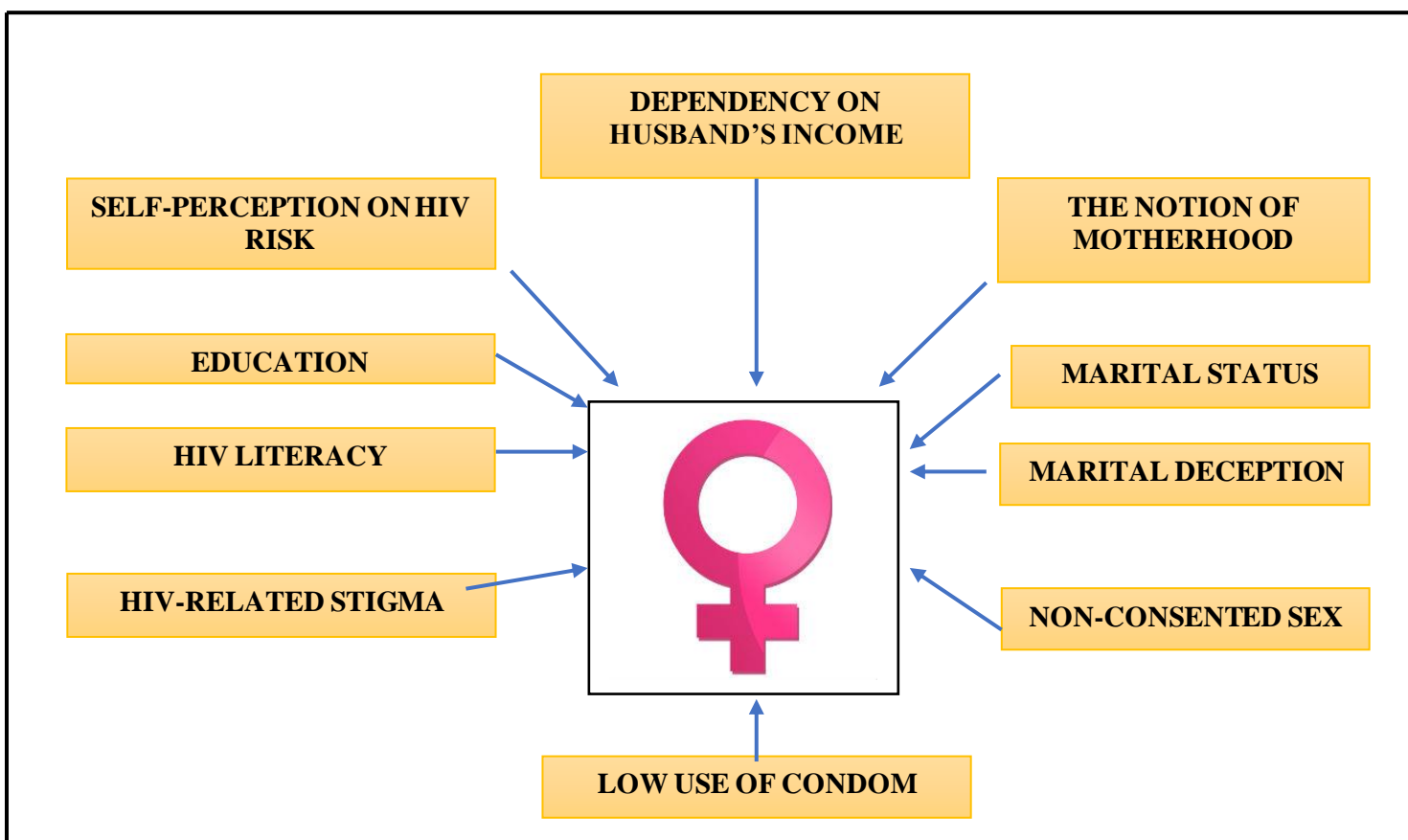


Figure 8.2: Women’s vulnerability to HIV infection in Indonesia: An Intersectional approach

In summary, women’s vulnerability in Indonesia is depicted by the intersections of the following factors depicted in Figure 8.2. The most common axes of disadvantage typically include: poverty, marital deception, low HIV literacy and dependency on husband’s income. Most importantly, these findings may help us understand why PMTCT programmes need to address multiple barriers caused by different intersected elements based on lived women’s experiences in the Indonesian context. These elements include gender discrimination,

behaved wife, or an immoral woman. The stigma related to HIV is internalised by the women, society and healthcare workers (Butt, 2015; Mahajan et al., 2008; Sangaramoorthy et al., 2017; Stangl et al., 2019).

A group of healthcare workers (HCW) in my study agree that HIV-positive women may be stigmatised by the health system. Healthcare workers have a responsibility to access the woman's right to PMTCT services and for them to be treated fairly. One group of healthcare workers argued that they have the best intention to provide HIV-related services and are aware that HIV-positive women have rights to access the best of PMTCT services. Therefore, some health workers have been trained to treat and refer HIV-positive women from primary health services to tertiary hospitals and they have regular meetings to ensure HIV programmes, including PMTCT services, are correctly delivered.

On first glance, it would appear that there was no difference between the treatment of HIV infected women and other women. The women did not have to queue (which usually took an hour) at a registration desk to take ARV medicine. On another occasion, two HIV-positive mothers with their HIV children expressed their experience that malnourished children were treated for almost a month in a hospital. However, these children were then moved from a shared in-patient room, to a private room after HIV diagnosis. I observed in the same hospital a doctor who wrote a clear referral letter with: "pregnant woman 38 weeks with HIV" before her delivery. I argue HCWs may not be aware that these actions were interpreted by HIV-positive women as unfairness or discrimination in health settings (Mahajan et al, 2008; Sangaramoorthy et al., 2017; Stangl et al., 2019).

HCWs may perform discriminatory practice due to pre-existing stigma related to HIV-positive women. Dominant cultural beliefs or negative stereotypes link to PLHWH are: (1) an HIV-infected a woman may choose a *suami tidak baik* (bad husband), (2) parents of HIV-infected children may not be 'good' or 'proper' parents (*bukan orang tua baik-baik*) and (3) HIV is a disease due to one's behaviour (*penyakit yang dicari dewek/sendiri*) (Najmah, field notes, 2017, 2018). Such labelling of HIV-positive women as not a good woman could be seen as normal as it was collectively observed amongst health professionals within a particular setting. HIV related to stigma can result from institutionalised discrimination towards HIV-positive mothers and wives (Butt, 2015; Butt et al., 2017; Imelda, 2014). The stigmatising behaviour may be unintentional, however, staff in the health setting that I visited had normalised their discrimination (Thomson, 2012).

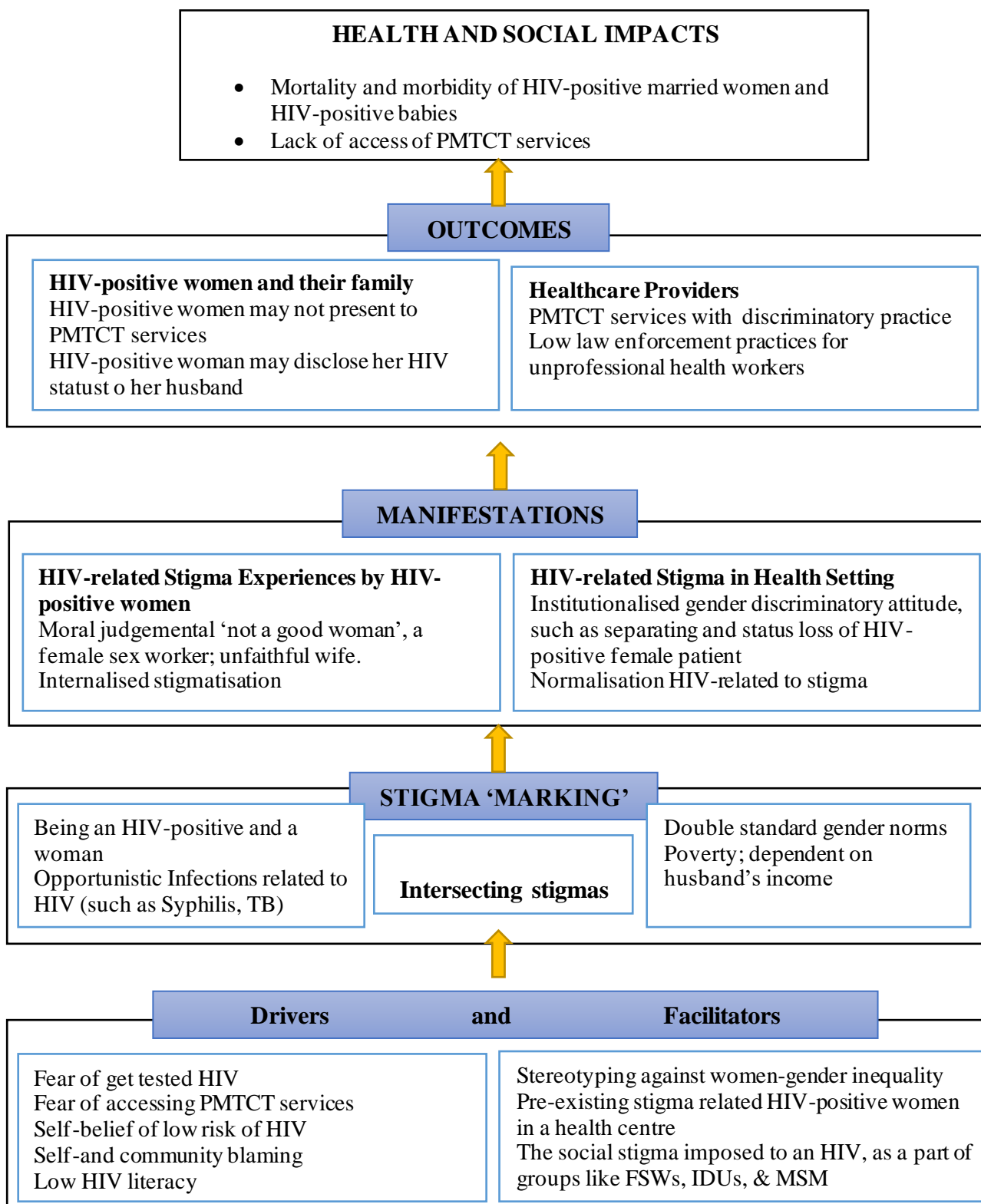


Figure 8.3: HIV-related stigma in Indonesian context (adopted from Stangl et al., 2019)

stigma amongst HIV positive women. Mano's internalised HIV stigma had become her personal entrapment and barriers to accessing HIV test and treatment. Self-imposed stigma was then translated into personal grief and loss and shame. Mano lost her hope, loss of dreams, loss in the battle to raise her only child and to have a happy family. After her death, Mano's parent took care of her son. From Mano's story, I learn that for women who have accessed HIV services, including PMTCT services, sexism and stereotyping intersect with HIV-related stigma.

The current study adds to further understanding that men are less likely to have a morality judgement placed on them to permit them more access to be a stigmatised user of healthcare services than women living with HIV (Bottorff, Oliffe, Robinson, & Carey, 2011; Risal & Gunawan, 2018). Healthcare providers may exacerbate HIV-related stigma towards women living with HIV if gender inequality and moral double standards persist (Hampananda, 2012; Hlartaithe et al., 2014). The present studies provide different experiences of HIV-positive women, as one of impacts of HIV-related stigma. One is that a husband must give approval for his wife's HIV test, but if his wife is diagnosed with HIV, the husband will not necessarily voluntarily undergo HIV testing, despite knowing his wife's HIV status. Another example is that a husband may also refuse an HIV test for himself and his wife. Yet, after knowing that his wife is HIV positive, he may still reject HIV testing for himself. If the husband passes away, an HIV-positive widow may deal with multiple HIV related stigmas; without a family support, this condition may exacerbate the mental and physical health problems of the woman.

Women with multiple intersection of unprivileged elements, therefore, may contribute to a cumulative effect on HIV-related stigma and women's vulnerability to their access to PMTCT services. Consequently, not all health workers can exercise their professional responsibilities to conduct HIV testing of husbands or partners with wives who are suspected or confirmed as having HIV. For the women from low-income family or dependent income to her husband, she may or may not be offered HIV testings after her husband's diagnosis of HIV or health workers only inform about husband's HIV status to family of her husband, not to his wife (see marital deception, the first section of this chapter). The most interesting finding was that discrimination toward HIV and women has become normalised and accepted in health settings (see Butt, 2011).

The evidence in this study suggests that HIV-related stigma often promotes discrimination and a narrow vision of HIV. For example, an HIV-infected woman is often considered as not a

countries categorised as low HIV epidemic countries. Nguyen et al. (2008), Riono and Jazant (2004) and Thisyakorn (2017) discussed the Asian HIV epidemic model of key populations at higher risk of HIV exposure and women in general populations. These Asian studies highlighted the increasing number of HIV infections among heterosexual married women and men, as condom use is still not commonly practised in Asia. These studies, arguably, tend to destigmatise certain groups, such as IDUs, MSM, transgender and female sex workers, all of whom are categorised as anti-social or immoral. The decriminalisation of certain groups creates less awareness for women in the wider population (such as mothers and married women), of their own HIV status.

These findings contribute in several ways to understanding of women's vulnerability to HIV in Indonesia, particularly among mothers and wives and provide an important rationale for creating awareness of PMTCT for women in the wider population. There are four likely possibilities that women, particularly *ibu rumah tangga*, may increase HIV transmission with or without awareness of their HIV status. Firstly, there is no compulsion for unfaithful husbands to disclose their infidelity to their wives. Secondly, there is no legal imperative for those who know of a husband undertaking risky behaviours (such as intravenous drug use or adultery or being MSM), to tell his wife. Thirdly, there is no provision for *ibu rumah tangga* to be tested for HIV, and no encouragement or demand that they do. Fourthly, men or women who contract HIV often knowingly transmit HIV to their husbands or wives, and later, if a woman becomes pregnant, there is a greater risk of mother-to-child HIV transmission. My finding provides clear support for Jacobowski's hypothesis that in Indonesia "marriage is not a safe place" (2008, p. 87) from HIV infection due to the possibilities discussed. Therefore, without awareness of HIV among women, the findings of this study support Rahmalia et al.'s work (2015), that proposed the hypothesis that HIV-positive women may link HIV "from concentrated epidemic to the wider community" in Indonesia (p.1). My finding repudiates the common assumption that women in the wider population are not responsible for spreading HIV, with or without their awareness of being HIV positive (MoH, 2012b; Nguyen, et al., 2008; Riono & Jazant, 2004; Thisyakorn, 2017).

This phenomenon of marital deception and HIV-related stigma in family, kinship and healthcare provides a clear explanation of a silent epidemic in the wider population. A first step in providing care must be empowering wives, husbands and doctors to talk about sexual relations outside marriage, sexual histories, gender identity (such as men having sex with men)

Chapter 9. Translating Research Knowledge into Practice



Note: The English translation of the words in this picture is: We are great mothers (*kami Ibu Hebat*). HIV is not a death penalty (*HIV tidak mematikan*). We survive with HIV/AIDS (*kami tetap bertahan hidup meski dengan HIV/AIDS*). Let's get an HIV test (*mari kita tes HIV*). People living with HIV (PLWHIV) are not scary (*Penderita ODHA tidak menakutkan*). We wish for all HIV-positive people to always strive (*semoga ODHA sukses terus*). Please, stop discrimination against those living with HIV (*hapus diskriminasi HIV/AIDS*). Government needs to embrace PLWHIV (*pemerintah merangkul ODHA*); Keep your spirit up (*semangat!!*). Someday, we hope there will be a cure for HIV (*berharap suatu saat ditemukan obat untuk menyembuhkan HIV*). I am HIV-positive (*Saya HIV +*).

The above picture was produced during my final FGD with 10 of the 18 HIV positive women who participated in this study. The handwritings and handprints on the white cloth reflect the motivation, spirit, and hope of those 10 women. Two of the messages are “please eliminate discrimination towards PLWHIV” and “let’s do an HIV test”.

This chapter focuses on HIV women’s aspiration and the actions (such as visual outcomes) to provide solutions for better access to PMTCT services to meet women’s needs. I believe that, given a safe and collectively trusting space, HIV-positive women can consciously and critically propose actions that will enable them to have better access to PMTCT services in Palembang, Indonesia. The research was largely informed by FPAR, following the work of Patricia Maguire (1987, 1996, 2006), Brinton Lykes (2007; 2014; 2012), and Collen Reid and Wendy Frisby (2008) which endorses the centrality of women’s voices, aspirations, and ideas. In my study, FPAR also offers an intersectionality lens for understanding the complex reality of the lives, health decision-

Table 9.1 Summary recommendation across four prongs of PMTCT programmes

Prong	Related program	Participants' views	Recommendations	Related to chapter
1. Prevention of HIV among women of reproductive age	IEC or KIE	<ul style="list-style-type: none"> • IEC is expert driven • The use of loaded and judgemental language is counterproductive which promote victim blaming 	<ol style="list-style-type: none"> 1. The use of simple, locally relevant and non-judgemental languages for IEC <ul style="list-style-type: none"> ○ Normalisation of HIV testing, such as open discussion and promotion of the test to pregnant women as like any other immunity tests or blood tests for a regular check-up. ○ Uniform message for health promotion and communication (such as all women are vulnerable to HIV transmission, not the only family with an unfaithful husband). 2. HIV messages to be relevant to different stakeholders 3. The use of relevant media and social media in delivering IEC messages. 	3, 7

Prong 1: Plan of action for prevention of HIV among women of reproductive age

Prong 1 focuses on HIV prevention strategies for women of reproductive age, and their husbands. Foci of Prong 1 include developing materials and media for Information, Education and Communication or IEC (*komunikasi, informasi, edukasi or KIE*) on HIV screening and PMTCT services. According to participants in this study, effective IEC on PMTCT services need: 1) to be relevant to the women's cultural and social lives and local expression and utterance presenting in a simple non-judgmental language; 2) to use relevant media (including social media); and 3) to collaborate with diverse groups of people relevant to HIV to make an initial change.

Prong 1 - Recommendation 1: Using a simple, local-relevant and non-judgmental language

My findings highlight the fact that any sexually active Indonesian woman is vulnerable to HIV transmission (Chapters 5 and 8). The fact is that unfortunately, women found no easily accessible information. Yet when HIV information was available or offered to them, such information was inadequate, complicated, or expert-driven. My participants expressed concern about HIV messages that were made them scared or feel bad about themselves.

HIV-positive women were adamant that the HIV test needs to be normalized and the promotion of HIV testing needs to reach to all women. Therefore, IEC materials need to make it very clear that 'all women are vulnerable to HIV transmission, including mothers and wives'. My participants were concerned that a decision to offer an HIV test had so far been about the discretion of the health providers. Consequently, many women may fail to seek and/or obtain important information about HIV testing, for example, during pregnancy. My participants on many occasions, emphasised that HIV awareness messages ought to use simple language and not to convey any moral judgmental.

Some examples of HIV health promotion messages were developed by groups of HIV-positive women in this study. For instance, messages such as, 'HIV as an immunity test for mothers and children' and 'HIV test is not scary' were easily understood and accepted. The participants also believed in the important use of a warm and caring message: 'let's protect mothers, children, and health workers from HIV' and messages that show the value of altruism focusing on collective (family, society) efforts to HIV prevention: 'Uncle, aunt, and other family members, please engage your family to take

and health professionals (such as, midwives and specialists) (Chapter 7). For example, these three different groups of stakeholders have different language lexicon and utterance, and focus when they were asked how to enhance current HIV test policies and program.

The group of midwives wanted to focus on getting regular, relevant training on HIV services and the provision of HIV test kits. Those participants from NGO affiliations aspired to focus on funding prioritizing community-based programmes and community empowerment. Health specialists suggested practices and policies address stigma leading to poor access and unprofessionalism in HIV screening programmes. When these messages were shared across different stakeholders (including Palembang and South Sumatra PHO, hospitals, and *puskesmas*), all agreed that those messages were complementary and could be shared amongst all of them. The above-mentioned, complexities of the use of language, lexicon, media, audience, and intentions of the messages made require programmes and policies to look into a new way, a transformative way, of developing, delivering and promoting IEC on HIV prevention across different sectors.

I propose existing programs look into various stakeholders and advocate partnership for responsive transformative change. A group of HIV-positive women, NGO workers, and health workers proposed a proactive and multi-sectoral collaboration in developing IEC messages which are relevant to different stakeholders (i.e. HIV positive women, families, midwives, and specialists). Hence, I have learned that the central role of myself as a researcher, NGO workers, and health workers is in building participation, community mobilization, and community trust of HIV-positive women in this study.

In this study, online discussion forums and community consultation were proven to be an effective way to share HIV messages in different safe spaces amongst the groups. Ownership and participation of stakeholders are the keys to successful programme for IEC. Resources needed may include a community or online workshops, training on choosing the best visual media to deliver messages to different groups of stakeholders; and raising awareness and knowledge to choose the non-stigmatizing, simple, and relevant language that will be discussed in section 2, FPAR, of this chapter.

service within PMTCT in Indonesia and the promotion of condoms used warrant further study.

Prong 3: Plan of action for preventing HIV transmission from a HIV-positive woman to her unborn baby

Prong 3 aims to eliminate mother-to-child HIV transmission (MTCT). Of these four prongs, Prong 3 has been very dominant in PMTCT programmes in Indonesia and globally (Badriah, Tahangnacca, Alkaff, Abe, & Hanifah, 2018; Idele, Hayashi, Porth, Mamahit, & Mahy, 2017). Services provided within Prong 3 include antenatal HIV testing and the provision of ARV therapy; safe childbirth, and prophylaxis therapy for babies born to HIV-positive mothers. Hence, participants in this study recommend two effective plans of action for Prong 3 of PMTCT services: 1) midwives as a central role of HIV screening and 2) right-based training for health professional on universal health access.

Prong 3 – recommendation 1: Giving midwives a central role in HIV screening

Normalising HIV testing for women in the general population is urgently needed. One way this normalisation can be achieved is by creating a partnership between local or private midwives within PMTCT services. The majority of HIV-positive women who participated in this research had, at some point in their pregnancies, visited their local midwives⁷³. According to the participants, local midwives could play a key role in HIV screening by offering the “3M” or “3 OEA” which stands for *menawarkan* (offer), *mengajak* (engage), and *menemani* (accompany) women to services.

My findings confirm the following evidence:

- First, HIV testing was not yet readily available in all *puskesmas* or community health centres and hospitals in Palembang as well as other cities or regencies in South

⁷³ I noted that midwives are often the first contact of pregnant women to health services. Local midwives are generally well respected and well known by the communities and provide affordable cost. Most of the private midwives have their practice in their homes, therefore they have more flexible hours (Lubis, Wulandari, Suariyani, Adhi, & Andajani, 2019).

useful to promote knowledge sharing, resourcefulness, and most relevant and creative solutions to problems challenges (Reid & Frisby, 2008).

Midwives also aspire for other supportive factors to normalise HIV testing. PHO needs to provide free HIV test kits for private midwives as well as supportive leadership within local and regional PHOs to upskill midwives' knowledge and practice in PMTCT. Furthermore, often a midwife needs to accompany her clients who have been confirmed HIV-positive at *puskemas* or the hospital, therefore transportation cost can be quite dear and it needs to be reimbursed to the midwife.

In summary, normalization of HIV stigma, therefore, needs to be addressed in current health settings in Indonesia, in all levels. Midwives could be central to this effort. Training of midwives needs to challenge midwives to be an agent of change to counter HIV-related stigma. When this Ya-Saman song was shared with HIV positive women, the song was applauded and HIV positive women believed their aspiration was well aligned with their midwives. Therefore, early diagnoses of HIV in pregnant women is a priority for both pregnant women and midwives in any PMTCT programmes.

Prong 3 – recommendation 2: Rights-based training for health professional on universal health access

Health workers needed to have adequate knowledge and skills to overcome fears in dealing with HIV-positive women accessing PMTCT services. Findings from my study reiterate the key message that all women are vulnerable to HIV and that no - *ibu rumah tangga* – is immuned to HIV. The study shows that different perspectives of HIV stigma that reinforce the normalisation of institutionalised discrimination in people with HIV and those working with HIV patients. While people (read women) living with HIV are often to be victimized by social stigma and condemnation; health workers maybe ones who reinforce and sustain that social stigma toward women living with HIV.

The right-based training approach, therefore, is required as the foundation of the protection, respect, promotion and fulfilment of women's rights to health; women's rights to access the best health care services; women's rights to be treated with respect and dignity; women's rights to confidential treatment; and women's rights to an informed-decision. All of these women's human rights are well noted, especially in the Convention on the Elimination of all Forms of Discrimination Against Women in 1985

First Principle: Cultivating trust with women

Building trust is the first important stage in PFAR research (see Lykes & Crosby, 2014; Maguire, 1987). From this research, I began to recognize various indicators of trust-building outcomes (also read the second and third principles), such as participants' confidence in honestly sharing their expression and authenticity using local colloquial language. Participants' explanation of the context of discrimination experienced, types of discrimination, and feelings being discriminated enriched our collective understanding of discrimination in the HIV context.

I was made aware of the shift of representation made by my participants before and after they felt confident and trust their groups and my research process. For example, at an earlier stage, I was somehow aware of their fears of my judgment toward them and they did not take my promise as 'I will not judge you' at a face value. Only after several meetings inside and outside the research workshop, did some participants start to openly share their deep and private secrets and lives. For example, some told me of them being sex workers, former IDU, and being in a polygamous marriage. Such topics are generally very taboo to be discussed especially with a new person. Interestingly, one participant said, "finally, I met someone to share my story that I kept secret for ages; I hope other women will learn from my story" (Mona, 2017).

For me, it was important to honour their trust by protecting their confidentiality and always clarify my understanding and what I wrote in my field research diary with my participants. I ensured them the confidentiality of their information and identities and that they could ask me to omit their stories in my thesis or publication. One key lesson I gained as a novice PAR researcher was on the challenges to present authentic voices of my research participants, that I need to build trust in my research process.

Second Principle: Creating a space for non-discriminatory and open dialogue with a critical analysis of gender relations

I was fully aware that my participants might have seen me as an outsider: an academic, lecturer, overseas graduate, and an HIV-negative woman. Based on my experience, the key to creating non-discriminatory open dialogue was an awareness of my privilege and my participants' position and the power dynamics in our partnership. This principle is consistent with that of Lykes and Crosby (2014), who defined open dialogue as 'a way

them, accompanied some to a hospital before their delivery, provided space for their children during FGDs (e.g. providing drawings and snacks), and let them know my children and their children to have a play date with my children. I suggest that understanding participants' local customs, tradition, and values are an essential step in the first engagement with participants. My practice of local customs supports Yoshihama and Carr (2002) and Senarak, Chirawatkul, and Markovic (2006) that noted the importance of a PFAR researcher to have an awareness of and appropriate response for local norms and values.

Through an open, non-discriminatory, and reflective dialogue I also learned to notice individual strengths and capacities that each participant brought to the creation of our collective knowledge. I see the skills to facilitate an open, authentic, and reflective dialogue as central to any qualitative research.

Third Principle: Centring women within a safe physical environment

In this research, I learned on how to create “a safe space” that centred around women's social and relevant life context as well as appreciating diversity, attitudes of caring and compassion and egalitarian understanding of power [e.g. Ponc, Reid, and Frisby (2010, p. 333)]. Within their chosen safe, physical, and supportive environments my participants exercised a sense of freedom of expression. They were not only sharing their vulnerability and challenges faced by being HIV-positive, but also their hopes and recommendation for PMTCT services and policies.

Thus, I always asked participants to decide on the location for our interview or FGDs. I became aware of the importance of this question when two participants decided to withdraw from the study due to concerns about their privacy, as they had not disclosed their positive HIV status to their husbands. Other women, however, were happy to meet in open areas for FGDs, such as in a public park. The term ‘B20’ was used by participants to refer to their HIV. I also offered them to have discussion sessions in a private space, for example, when they needed to work on their visual project. Others preferred to meet me in their house or office or a hospital café.

process in which people come together to share experiences through a dynamic process of action, reflection and collective investigation”, but in the same actions produced remain “firmly rooted in participants own conceptual and in the interaction between them” (p. 179).

Upon returning back to New Zealand for my writing, I learned that some of the videos produced by participants in this research had been uploaded on social media and had ‘gone viral’ and shared by over 200 health workers through Facebook. Another community based imitative was the launch of a programme “\$1 for HIV-positive children supported by the Public Health Alumni Association of Sriwijaya University (IKA FKM Unsri), Palembang (Figure 9.2)”, written in the Palembang Post newspaper, 5 December 2018.



Figure 9.2 A social programme of Rp 10,000 untuk ADHA (movement of “\$1 for HIV-positive children”)

Note: IKA FKM Unsri, (*Ikatan Alumni Fakultas Kesehatan Masyarakat Universitas Sriwijaya - Public Health Alumni Association of Sriwijaya University*).

Sixth principle: Proposing an intersectionality lens: accommodating the multi-layered and complex interactions of the socio-cultural and political context of women’s lives

Using FPAR methodology, I gathered more insights and understanding on the translations of intersectionality of gender, social classes, access and relevant HIV

2. Small number of HIV positive female participants

The number of HIV positive female participants (18) was relatively small and findings of this research are not generalizable to a wider Indonesian population groups with diverse ethnicities, linguistic and social religious and cultural backgrounds. This size of participants however, had allowed this research to small and close group workshops and participation, which is a key principal in FPAR. To allow triangulation of data, I also recruited health providers (mostly midwives) and NGO workers. Yet, I believe this study also provide theoretical contribution to current scholarships on intersectionality, HIV stigma, and marital deception which could be relevant to other not only Indonesian society but also internationally.

Study site

All the participants in this study were residents of Palembang city and were mostly Muslims and of Malay ethnicity. A few participants were migrants to Palembang and had lived in other Indonesian islands. Therefore, the generalization of this study findings is limited to people of the same characteristics as those participated in this study. Further research in different provinces in Indonesia with different ethnicities and religious beliefs is required to extend these research findings.

Time limitation

I spent four months in the field. Therefore, it was very challenging to allow for a full participation of my participants in the early design of this research. Participations were mostly on the way knowledge and actions production. The research questions were developed prior to the field work. Although the research objectives were achieved, I believe that impact of this research findings and disseminations of the actions will continue, well beyond my doctoral research. For example, future research may look into the impact of the research findings in a longer-term period.

Information bias

People living with HIV are widely stigmatized in Indonesia. It was possible that participants had consciously hid information from me and they might have had screened their stories to express mainly good things about themselves. Such challenges are not new to qualitative research. Likewise, participation was voluntarily, and no participants were forced to share information they were not comfortable to share with the researcher.

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Appendices

Appendix A: Ethics approvals

Appendix A.a: Ethics approval from Auckland University of Technology

AUTEC Secretariat

Auckland University of Technology

D-88, WU406 Level 4 WU Building City Campus

T: +64 9 921 9999 ext. 8316

E: ethics@aut.ac.nz

www.aut.ac.nz/researchethics

7 March 2017

Sari Andajani

Faculty of Health and Environmental Sciences

Dear Sari

Re Ethics Application: **17/22 Enabling positive HIV-women of childbearing age to access Prevention of Mother to Child (PMTCT) services in Indonesia**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 6 March 2020.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 6 March 2020;

- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 6 March 2020 or on completion of the project.

It is a condition of approval that AUTEK is notified of any adverse events or if the research does not commence. AUTEK approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEK grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor

Executive Secretary

Auckland University of Technology Ethics Committee

Cc: thn2949@autuni.ac.nz; Sharyn Graham Davies

Appendix A.b: Ethics approval form University of Sriwijaya, Indonesia



KEMENTERIAN RISET, TEKNOLOGI DAN PENDIDIKAN TINGGI
UNIVERSITAS SRIWIJAYA
FAKULTAS KEDOKTERAN
KEPK FK UNSRI/RSMH
Jalan Dr. Moh. Ali Komplek RSMH Palembang 30126 Telpun (0711)352342 Faksimile (0711)373438
Email tu@unsri.ac.id



Rumah Sakit Umum Pusat Mohammad Hoesin dan Fakultas Kedokteran Universitas Sriwijaya
Mohammad Hoesin Central General Hospital and Faculty of Medicine Sriwijaya University

Komisi Etik Penelitian Kesehatan
Health Research Review Committee

SERTIFIKAT PERSETUJUAN ETIK
ETHICAL APPROVAL CERTIFICATE

No. 39/kepkrsmhfkunsri/2017

Komisi Etik Penelitian Kesehatan Rumah Sakit Umum Pusat Mohammad Hoesin Hospital dan
Health Research Review Committee of Mohammad Hoesin Central Hospital and

Fakultas Kedokteran Universitas Sriwijaya, Palembang, Indonesia,
Faculty of Medicine, Sriwijaya University, Palembang Indonesia

berdasarkan penilaian terhadap proposal penelitian, dengan judul:
based on the review on research proposal, entitled:

Memampukan Ibu HIV Positif Usia Subur untuk Mengakses Layanan Pencegahan Penularan
HIV dari Ibu ke Anak (PPIA) di Indonesia

*Enabling Positive HIV Women of Childbearing Age to Access Prevention of Mother to Child
Transmission (PMTCT) Services*

atas usulan peneliti:
proposed by the researcher:

Najmah

dari Bagian Ilmu Kesehatan Masyarakat
from the Department of Public Health Sciences

dengan mengacu pada Pedoman Nasional Etik Penelitian Kesehatan beserta suplemennya
referring to National Ethical Guidelines on Health Research and its Supplements

dengan ini menyatakan bahwa penelitian kesehatan tersebut
hereby declares that the proposed health research is

layak etik; dan disetujui untuk dilaksanakan di lingkungan
ethically liable; and is approved to be carried out within

Rumah Sakit Mohammad Hoesin dan Fakultas Kedokteran Universitas Sriwijaya
Mohammad Hoesin General Hospital and Faculty of Medicine Sriwijaya University

Palembang, 13 Maret 2017



Prof. dr. Hermansyah, SpPD-KR, FINASIM, CCD
Ketua Tim Penilai/Ketua Komisi
Team Leader of the Reviewer/Head of the Committee

Appendix B: Tools

Appendix B.a: Participant Information Sheets

B.a.1: (English) For focus group discussions with HIV-positive women aged 15 to 49 years

PARTICIPANT INFORMATION SHEET

Date Information Sheet Produced: 31 January 2017

Project Title

Enabling HIV-positive women HIV-positive women aged 15 to 49 years to access Prevention of Mother-to-Child Transmission Services in Indonesia

An Invitation

Assalamu'alaikum warohmatullahiwarokatuh

Hi, I am Najmah, a Ph.D. student in the school of Public Health and Psychosocial Studies, Auckland University of Technology, New Zealand. I am also a mother of two children and stay in Palembang. I would like to invite you to participate in my study. This study is a requirement of my doctoral degree.

I will be the primary researcher of this study. My supervisors are Dr. Sari Andajani and Assoc. Prof. Sharyn Graham Davies.

Your participant is voluntary (your choice). You can withdraw or leave this study at any time prior to completion of data collection and without giving me any explanation.

What is the purpose of this research?

The aim of this study is to create a space for positive-HIV mothers' ideas and aspirations to enable them to access Prevention of Mother-to-Child of HIV Transmission (PMTCT) services. Research questions in this study are: 1) what factors enable HIV-positive women to access PMTCT services?; 2) What are the best strategies for enabling HIV-positive women to access PMTCT services; and 3) How are these strategies implemented?

In the future, I will present the results of this study in my Ph.D. dissertation and seminars related to the topic. In addition, I intend to publish outputs of my research project in journals, a conference paper or other academic publications or presentations.

How was I identified and why am I being invited to participate in this research?

You were identified to participate in this research because you have contacted me and you have met the eligibility of the research, being a woman with HIV and aged 15 to 49 years.

You are invited to participate and respond to this research after:

1. Reading/looking at an advertisement of the study
2. Obtaining information from peer supports or HIV related NGO who may pass on the contact details of the researcher to their clients and networks through word of mouth.

3. Attending a further information session about this study, particularly for illiterate participants who are interested to know about this study from their networks.

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You will need to complete the informed consent and release consent of any visual output, and sign these forms if you agree to participate. You are able to withdraw from the study at any time prior to completion of data collection. If you choose to withdraw from the study, it may not be possible to destroy all records of the focus group discussion of which you are a part, you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

Up to six focus group discussions will be conducted during this study. The schedules and places of meeting will be arranged by a group consensus at an informal meeting place, for instance, NGO office, a restaurant that provides a private space. A group activity will be combined with one or two of the following visual methods, like drawings, mind -mapping, and/or a collage or traditional oral expression like poems.

Topics will be explored related to the aim of this study, including about the understanding about PMTCT, barriers to lack of accessibility of PMTCT services, factors that activate HIV -positive women to access PMTCT services, and ideas related to the enhancement of the accessibility of PMTCT services.

What are the discomforts and risks?

You might experience a level of discomfort because I, and other members of focus group discussion, will know your HIV status. In addition, during the group discussion, you may feel uncomfortable and upset to talk about your lives, motherhood and HIV and your family.

You might be not comfortable if your husband/partner knows about your participation in this research.

You might be not comfortable if your friends, family, or neighbours might be seen and meet you with me in a public area during this study.

How will these discomforts and risks be alleviated?

I will support you with empathy, and be a good listener during focus group discussions. I will not be judgemental with your HIV status.

Every member of the focus group discussion has to sign a consent form not to share our discussion and identity of focus group discussion members to people outside of the focus group discussion members.

You will be given an option not to answer some questions.

If you don't feel comfortable, cannot answer the questions, or feel sad or anxious in answering any questions or continuing with the interview, please inform the researcher. You will be asked if you wish to pause or perhaps do the interview at another time.

It is not easy to delete some parts of your voices from all focus group discussion recordings during group discussion, but you have the right not to include your voice for further data analysis or to leave the focus group discussion without providing any reasons.

The focus group discussion will mainly be conducted, where possible, in a private area, like the NGO's office. If not, I will replace the words HIV with other names of diseases, like a toothache during an interview in public places.

When requested, the principal researcher and/or a research facilitator will be open to a request for explaining this research to the woman's husband if necessary.

Professional counselling related to HIV will be provided if you require to use it.

What are the benefits?

Participants

This study might not directly give benefits to you. However, through your involvement in this study, you will be given a space and permission to freely express your concerns, give voice, and choose any means (methods) that will enable you to express your ideas and concerns. The significance of this research lies in providing a space for HIV-positive women to share their ideas and aspirations to develop strategies for best access to PMTCT services from your own perspectives and subjective life context. In addition, a nominal transportation voucher/money and lunch or refreshment will be provided in each session of group discussion.

The wider population

Findings from this research will benefit the wider Indonesian community and South-East Asian region as a case study concerning women's access to PMTCT services, and women's participation in voicing your ideas and aspirations for better access to PMTCT services in the region. For other countries that are predominantly Muslim, it is anticipated that women might reflect their concerns within their religious or social context.

For researcher

This field research is contributing to the completion of a doctoral study for Najmah. Experiences and knowledge gained from this research will enhance the primary researcher's skills and knowledge in participatory action research and her future work within PMTCT services, policies, and programmes in Indonesia.

How will my privacy be protected?

Before starting any data collection, you will be given, and explained, an information sheet related to this study. Then, if you agree to get involved, I will ask you to sign a written informed consent and release consent form.

All information will be strictly confidential. A unique code or a pseudonym name will be assigned for each participant in each transcript of a focus group discussion or publications. I am the only person who will know your details of a unique code or pseudonym name. I will limit the accessibility of transcript, visual methods, field notes and other research outcomes to my supervisors and myself, as primary researcher.

All documents related to this research, including transcript results, consent form, release form, visual output, field and reflection notes and other traditional oral expression will be held in a

locked cabinet at my supervisor's office at the School of Public health and Psychosocial Studies and Social Science Department in Auckland University of Technology, New Zealand.

What are the costs of participating in this research?

I would like to invite you to attend a focus group session that will take up to 3 hours. I would like you to attend up to 6 sessions (maximum 18 hours) to complete the data collection stages.

What opportunity do I have to consider this invitation?

You will be given up to two weeks to decide whether you wish to take part in this study. You can send me a text or an email to ask any questions or clarify any further information regarding the research.

Will I receive feedback on the results of this research?

A short leaflet containing the summary of research findings will be shared with you in the future through your peer supports in the NGOs related to HIV or the Health Office of Palembang.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified to the Project Supervisor, Dr Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, +64 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Najmah, najem240783@gmail.com, +6285267412242 (Indonesia), +64 226460427 (Auckland)

Project Supervisor Contact Details:

Sari Andajani, sari.andajani@aut.ac.nz,

Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

**Approved by the Auckland University of Technology Ethics Committee on 7 March 2017,
AUTEK Reference number 17/22**

B.a.2: (Indonesian) Untuk diskusi kelompok terarah untuk ibu positif HIV

LEMBAR INFORMASI UNTUK PESERTA PENELITIAN

Tanggal lembar informasi dibuat : 31 Januari 2017

Judul Projek Penelitian

Memampukan ibu positif HIV dan ibu hamil positif HIV untuk mengakses layanan pencegahan penularan HIV dari ibu ke anak (PPIA) di Indonesia

Undangan

Assalamu'alaikum warohmatullahiwarokatuh

Hi, saya Najmah, mahasiswa S3 dari Jurusan Kesehatan Masyarakat dan Psykososial di Universitas Teknologi Auckland, Selandia Baru. Saya juga ibu dari dua anak kecil dan tinggal di Palembang. Saya bermaksud mengundang anda untuk berpartisipasi dalam penelitian ini. Penelitiain ini merupakan syarat dalam proses S3 saya.

Saya adalah peneliti utama pada penelitian ini. Pembimbing disertasi saya adalah Sari Andajani dan Sharyn Graham Davies.

Partisipasi anda adalah sukarela. Anda bisa mengundurkan diri atau meninggalkan penelitian ini kapan saya tanpa harus mengikuti hingga pengumpulan data selesai dan tanpa memberikan penjelasan apapun kepada saya.

Apa tujuan penelitian ini?

Tujuan dari penelitian ini adalah untuk memberikan ruang bagi ibu positif HIV untuk memampukan mereka untuk mengakses layanan Pencegahan Penularan HIV dari Ibu ke anak. Pertanyaan penelitian saya adalah 1) faktor apa yang mengaktifkan ibu positif HIV untuk mengakses layanan PPIA? 2) Apa strategi terbaik untuk memampukan ibu positif HIV untuk akses ke layanan PPIA? Dan 3) bagaimana strategi ini bisa direalisasikan?

Dimasa yang akan datang, saya akan mempresentasikan hasil studi penelitian ini dalam disertasi S3, dan seminar terkait topik penelitian ini. Saya juga akan berencana akan mempublikasikan hasil penelitian ini ke jurnal dan artikel prosiding dalam seminar ataupun kegiatan akademik lainnya.

Bagaimana saya diidentifikasi dan bagaimana saya diundang untuk berpartisipasi dalam penelitian ini?

Anda diundang untuk berpartisipasi dalam penelitian ini melalui selebaran iklan atau leaflet terkait penelitian ini yang disebar oleh LSM terkait HIV dan staf dari Dinas Kesehatan Kota Palembang ke partisipan yang potensial dalam jaringan mereka. Lebih dari itu, anda bisa diundang oleh kelompok sebaya anda dan staff LSM melalui mulut ke mulut. Anda dipilih untuk berpartisipasi dalam penelitian ini karena anda memenuhi kriteria penelitian ini.

Bagaimana saya menyatakan keikutsertaan (setuju) untuk berpartisipasi dalam penelitian ini?

Partisipasi anda adalah sukarela (pilihan anda) dan apakah anda memilih untuk berpartisipasi atau tidak dimana menurut anda akan menguntungkan atau merugikan anda. Anda perlu melengkapi dan menandatangani lembar informasi dan lembar pelepasan hasil visual dalam penelitian ini jika anda setuju ikut serta dalam penelitian ini. Anda bisa mengundurkan diri dari penelitian ini kapan saja. Jika anda memilih untuk mengundurkan diri dari studi ini, kemudian anda akan ditawarkan pilihan untuk memiliki hasil diskusi ini atau mengizinkan saya menggunakan hasil diskusi ini. Namun, ketika hasil penelitian ini sudah dianalisa lebih lanjut, penghapusan data terkait anda kemungkinan sangat sulit untuk dilakukan.

Apa yang akan terjadi dalam penelitian ini?

Empat hingga lima diskusi kelompok terarah akan dilakukan selama penelitian ini. Anggota kelompok akan mengatur tempat dan waktu pertemuan informal kita. Anda akan dijelaskan proses penelitian termasuk (jika anda tidak keberatan) berbagi foto, kliping (kumpulan gambar, koran, majalah, tulisan anda dsb), dan/atau menggambar atau membuat peta pikiran atau metode seni ala Palembang seperti Pantun selama diskusi. Beberapa topik terkait tujuan penelitian, termasuk pengetahuan tentang PPIA, kendala akses PPIA, faktor yang bisa mengaktifkan ibu positif HIV untuk akses layanan PPIA, dan ide terkait peningkatan akses layanan PPIA.

Ketidaknyamanan dan risiko apa dalam penelitian ini?

Anda mungkin mengalami tingkat ketidaknyamanan karena saya dan anggota kelompok diskusi akan mengetahui status HIV anda. Selain itu, selama diskusi, anda mungkin merasa tidak nyaman dan sedih untuk berbagi cerita tentang kehidupan anda, keibuan dan HIV, dan keluarga anda pada anggota kelompok diskusi. Anda mungkin juga merasa tidak nyaman jika suami/pasangan anda mengetahui anda ikut serta dalam penelitian ini. Dan juga anda juga mungkin merasa tidak nyaman, jika teman atau saudara anda melihat anda bersama saya di area/tempat umum.

Bagaimana ketidaknyamanan dan resiko ini bisa diminimalisir?

Saya akan bersikap positif, berempati dan menjadi pendengar yang baik selama proses wawancara dan tidak akan bersikap negatif terhadap status HIV anda.

Anda mempunyai pilihan untuk tidak menjawab pertanyaan yang diajukan

Tidak mudah untuk menghapus bagian diskusi yang melibatkan Anda, tetapi anda memiliki hak untuk tidak dimasukkan suara anda pada analisa selanjutnya/atau meninggalkan penelitian kapan saja tanpa alasan.

Tempat diskusi kelompok diutamakan di tempat yang memiliki tempat tertutup, seperti kantor LSM, jika memungkinkan, tetapi jika tidak, saya akan mengganti kata HIV menjadi nama penyakit lain, misalnya sakit gigi selama wawancara.

Jika diminta, peneliti dan asisten peneliti akan menjelaskan penelitian ini kepada suami and jika diperlukan

Pelayanan konseling profesional HIV akan disediakan, jika anda membutuhkan.

Apa manfaat penelitian ini?

Anda

Anda mungkin tidak mendapatkan manfaat penelitian ini secara langsung, namun keterlibatan anda pada studi ini, memberikan ruangan dan kesempatan untuk menyampaikan/mengekspresikan ide, suara anda dan memilih metode apa untuk membantu anda dalam

mengekspresikan ide, dan suara dan harapan melalui metode visual dalam penelitian ini berdasarkan perspektif dan konteks kehidupan anda.

Populasi yang lebih luas

Hasil penelitian ini juga bermanfaat bagi masyarakat Indonesia dan wilayah Asia tenggara karena studi ini fokus pada akses wanita pada layanan PPIA dan partisipasi wanita dalam menyampaikan dan menyuarakan ide dan aspirasi mereka untuk akses PPIA yang lebih baik pada wilayah ini. Untuk negara lainnya, terkhusus negara yang mayoritas Muslim, studi ini akan menambah pemahaman sebagai perempuan berdasarkan kehidupan agama dan sosial.

Untuk peneliti

Dengan melaksanakan penelitian ini, saya akan melengkapi persyaratan gelar S3 saya sebagai mahasiswa dan peneliti. Selain itu, pengalaman dan pengetahuan selama penelitian ini akan meningkatkan kemampuan penelitian saya dan pengetahuan saya dalam hal penelitian tindakan aktif dan pelayanan, kebijakan dan program PPIA di Indonesia.

Bagaimana kerahasiaan saya dijaga?

Sebelum memulai kegiatan pengumpulan data, anda akan diberikan dan dijelaskan informasi terkait penelitian ini. Kemudian jika anda setuju untuk ikut serta dalam penelitian ini, saya akan meminta anda untuk menandatangani form persetujuan tertulis dan form pelepasan tertulis.

Semua informasi sangat rahasia. Kode unik atau nama bukan sebenarnya akan digunakan untuk setiap partisipan pada setiap transkrip hasil interview, observation and publikasi. Saya yang hanya tahu untuk kode unik atau nama samaran. Saya juga akan membatasi akses hasil transkrip, metode visual, catatan lapangan, dan hasil penelitian lainnya hanya kepada pembimbing disertai saya.

Semua dokumen terhasil rekaman diskusi, dan hasil transkrip diskusi akan disimpan di komputer saya yang memiliki password. Hasil transkrip, lembar persetujuan, dan lembar pelepasan dokumen participant, visual outputs, catatan tangan, dan dokumen lainnya terkait penelitian akan disimpan pada lemari terkunci di kantor supervisor saya di Jurusan Kesehatan Masyarakat dan Psikososial, dan Departemen Ilmu Sosial di Universitas Auckland Teknologi dengan maksimal penyimpanan 6 tahun dari selesainya proyek penelitian ini.

Apa yang anda dapatkan sebagai kompensasi dalam penelitian ini?

Makanan ringan dan/atau makan siang bersama serta voucher transportasi akan disediakan, dan koha atau hadiah akan diberikan pada pertemuan terakhir penelitian ini di lapangan.

Berapa lamakah waktu saya untuk menjawab undangan ini?

Anda diberikan waktu hingga dua minggu untuk memutuskan apakah anda bersedia berpartisipasi dalam penelitian ini. Anda bisa mengirim sms atau email jika ingin bertanya lebih lanjut terkait penelitian ini.

Bagaimana saya akan menerima umpan balik atas penelitian ini?

Leaflet singkat terkait hasil kesimpulan penelitian akan diinformasikan kepada anda dimasa depan melalui kelompok sebaya pada LSM terkait HIV atau dinas kesehatan kota Palembang

Bagaimana jika saya mempunyai kekhawatiran tentang penelitian ini?

Jika anda memiliki kekhawatiran terhadap penelitian ini, silahkan menghubungi pembimbing disertasi saya Dr Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

Kekhawatiran terkait pelaksanaan penelitian dapat disampaikan pada sekretaris eksekutif dari AUTEK, Kate O'Connor, ethics@aut.ac.nz ,+64 921 9999 ext 6038.

Dengan siapa saya akan hubungi untuk informasi lanjut penelitian ini?

Silahkan simpan lembar informasi ini dan Salinan dari lembar persetujuan anda untuk keperluan referensi di masa akan datang. Untuk informasi lebih lanjut, silahkan hubungi

Kontak lengkap peneliti

Najmah, najem240783@gmail.com, +6285267412242 (Indonesia), +64 226460427 (Auckland)

Kontak detail pembimbing disertasi:

Sari Andajani, sari.andajani@aut.ac.nz,

Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

Disetujui oleh Komite Etik Universitas Auckland Teknologi pada 7 Maret 2017 dengan nomor referensi AUTEK 17/22

B.a.3: (English) For interviews with HIV-positive women aged 15 to 49 years

PARTICIPANT INFORMATION SHEET

Date Information Sheet Produced: 31 January 2017

Project Title

Enabling HIV-positive women aged 15 to 49 years to access Prevention of Mother-to-Child Transmission Services in Indonesia

An Invitation

Assalamu'alaikum warohmatullahiwabarokatuh

Hi, I am Najmah, a Ph.D. student in the school of Public Health and Psychosocial Studies, Auckland University of Technology, New Zealand. I am also a mother of two children and stay in Palembang. I would like to invite you to participate in my study. This study is a requirement of my doctoral degree.

I will be the primary researcher of this study. My supervisors are Dr. Sari Andajani and Assoc. Prof. Sharyn Graham Davies.

Your participant is voluntary (your choice). You can withdraw or leave this study at any time prior to completion of data collection and without giving me any explanation.

What is the purpose of this research?

The aim of this study is to create a space for positive-HIV mothers' ideas and aspirations to enable them to access PMTCT services. Research questions in this study are: 1) what factors enable HIV-positive women to access PMTCT services?; 2) What are the best strategies for enabling HIV-positive women to access PMTCT services?; and 3) How are these strategies implemented?

In the future, I will present the result of this study in my Ph.D. dissertation and seminars related to the topic. In addition, I intend to publish outputs of my research project in journals, a conference paper or other academic publications or presentations.

How was I identified and why am I being invited to participate in this research?

You were identified to participate in this research because you have contacted me and you have met the eligibility of the research, being a woman with HIV and aged 15 to 49 years.

You are invited to participate and respond to this research after:

1. Reading/looking at an advertisement of the study
2. Obtaining information from peer supports or HIV related NGO who may pass on the contact details of the researcher to their clients and networks through word of mouth.
3. Attending a further information session about this study, particularly for illiterate participants who are interested to know about this study from their networks.

What will happen in this research?

Up to three informal interviews will be conducted during this study. The schedules and places of the meetings will be arranged by you and me, for instance at an NGO office or a restaurant that provides a private space. An interview activity will be combined with sharing one or two of the

following visual methods, such as drawings, mind-mapping, a collage and traditional oral expression like poems. Topics will be explored related to the aim of this study, including the understanding of PMTCT, barriers and lack of accessibility to PMTCT services, factors to activate HIV-positive mothers to access PMTCT services, and ideas related to enhancing accessibility of PMTCT services.

What are the discomforts and risks?

You might experience a level of discomfort because I will know your HIV status. In addition, during the interview, you may feel uncomfortable and upset when talking about your lives, motherhood, and HIV.

You might be not comfortable if your husband/partner knows about your participation in this research.

You might be not comfortable if your friends, family, or neighbours might be seen and meet you with me in a public area during this study.

How will these discomforts and risks be alleviated?

I will support you with empathy and be a good listener during focus group discussions. I will not be judgemental regarding your HIV status.

You have to sign the informed consent form and a released consent form.

If you don't feel comfortable, cannot answer the questions or feel sad or anxious in answering any questions or continuing with the interview, please inform the researcher. You will be asked if you wish to pause or perhaps do the interview at another time.

You will be given an option not to answer some questions.

You will also have the right to delete all interview recordings during the interview or to leave the meeting without providing any reasons.

The main place for the interview will, if possible, be in a private area, like the NGO office. If not, I will replace the words HIV with other names of diseases, like a toothache during an interview in public places.

When requested, the principal researcher and/or a research facilitator will be open to a request for explaining this research to the woman's husband if necessary.

Professional counselling related to HIV will be provided if you require to use it.

What are the benefits?

Participants

This study might not directly give benefits to you. However, through your involvement in this study, you will be given a space and permission to freely express your concerns, give voice, and choose any means (methods) that will enable you to express your ideas and concerns. The significance of this research lies in providing a space for HIV-positive women to share their ideas and aspirations to develop strategies for best access to PMTCT services from your own perspectives and subjective life context. In addition, a nominal transportation voucher/money and lunch or refreshment will be provided in each interview session.

The wider population

Findings from this research will benefit the wider Indonesian community and South-East Asian region as a case study concerning women's access to PMTCT services, and women's participation in voicing your ideas and aspirations to better access PMTCT services in the region. For other countries, that are predominantly Muslim, it is anticipated that women might reflect their concerns within their religious or social context.

For researcher

This field research is contributing to the Ph.D. programme undertaken by the student researcher, Najmah. In addition, experiences and knowledge gained from this research will enhance her research skills and knowledge in participatory action research and PMTCT services, policies and programmes in Indonesia.

How will my privacy be protected?

Before starting any data collection, you will be given, and explained about, an information sheet related to this study. Then, if you agree to get involved, I will ask you to sign a written informed consent and release form.

All information will be strictly confidential. A unique code or a pseudonym name will be assigned for each participant in each transcript of an interview or publications. I am the only person who will know your details of a unique code or pseudonym name. I also will limit the accessibility of transcript, visual methods, field notes and other research outcomes to my supervisors and myself, as primary researcher.

All documents related to this research, including transcript results, consent form, release form, visual output, field and reflection notes and other traditional oral expression will be held in a locked cabinet at my supervisor's office at the School of Public health and Psychosocial Studies and Social Science Department in Auckland University of Technology, New Zealand.

What are the costs of participating in this research?

I would like to invite you to attend an interview session that will take up to 90 minutes. I would like you to attend up to three sessions (maximum 180 minutes) to complete the data collection stages.

What opportunity do I have to consider this invitation?

You will be given up to two weeks to decide if you wish to take part in this study. You can send me a text or an email to ask any questions or clarify any further information regarding the research.

Will I receive feedback on the results of this research?

A short leaflet containing the research findings will be shared with you in the future through your peer supports in the NGOs or the Health Office of Palembang.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified to the Project Supervisor, Dr Sari Andajani, sari.andajani@aut.ac.nz, +64 9 921 9999 ext. 7738

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, Kate O'Connor, ethics@aut.ac.nz, +64 921 9999 ext 6038

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Najmah, najem240783@gmail.com, +6285267412242 (Indonesia), +64 226460427 (Auckland)

Project Supervisor Contact Details:

Sari Andajani, sari.andajani@aut.ac.nz,

Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 7 March 2017
AUTEC Reference number 17/22

B.a.4: (Indonesian) Untuk lembar untuk ibu positif HIV

LEMBAR INFORMASI UNTUK PESERTA PENELITIAN

Tanggal lembar informasi dibuat : 31 Januari 2017

Judul Projek Penelitian

Memampukan ibu positif HIV usia subur untuk mengakses layanan pencegahan peluaran HIV dari ibu ke anak (PPIA) di Indonesia

Undangan

Assalamu'alaikum warohmatullahi wabarokatuh

Hi, saya Najmah, mahasiswa S3 dari Jurusan Kesehatan Masyarakat dan Psykososial di Universitas Teknologi Auckland, Selandia Baru. Saya juga ibu dari dua anak kecil dan tinggal di Palembang. Saya bermaksud mengundang anda untuk berpartisipasi dalam penelitian ini. Peneliti ini merupakan syarat dalam proses S3 saya.

Saya adalah peneliti utama pada penelitian ini. Pembimbing disertasi saya adalah Sari Andajani dan Sharyn Graham Davies.

Partisipasi anda adalah sukarela. Anda bisa mengundurkan diri atau meninggalkan penelitian ini kapan saja tanpa harus mengikuti hingga pengumpulan data selesai dan tanpa memberikan penjelasan apapun kepada saya.

Apa tujuan penelitian ini?

Tujuan dari penelitian ini adalah untuk memberikan ruang bagi ibu positif HIV untuk memampukan mereka untuk mengakses layanan Pencegahan Penularan HIV dari Ibu ke anak. Pertanyaan penelitian saya adalah 1) faktor apa saja yang mengaktifkan ibu positif HIV untuk mengakses layanan PPIA? 2) Apa strategi terbaik untuk memampukan ibu positif HIV untuk akses ke layanan PPIA? Dan 3) bagaimana strategi ini bisa direalisasikan?

Dimasa yang akan datang, saya akan mempresentasikan hasil studi penelitian ini dalam disertasi S3, dan seminar terkait topik penelitian ini. Saya juga akan berencana akan mempublikasikan hasil penelitian ini ke jurnal dan artikel prosiding dalam seminar ataupun kegiatan akademik lainnya.

Bagaimana saya diidentifikasi dan bagaimana saya diundang untuk berpartisipasi dalam penelitian ini?

Anda diundang untuk berpartisipasi dalam penelitian ini melalui selebaran iklan atau leaflet terkait penelitian ini yang disebar oleh LSM terkait HIV dan staf dari Dinas Kesehatan Kota Palembang ke partisipan yang potensial dalam jaringan mereka. Lebih dari itu, anda bisa diundang oleh kelompok sebaya anda dan staff LSM melalui mulut ke mulut. Anda dipilih untuk berpartisipasi dalam penelitian ini karena anda memenuhi kriteria penelitian ini, sebagai ibu positif HIV atau ibu hamil positif HIV.

Bagaimana saya menyatakan keikutsertaan (setuju) untuk berpartisipasi dalam penelitian ini?

Partisipasi anda adalah sukarela (pilihan anda) dan apakah anda memilih untuk berpartisipasi atau tidak dimana menurut anda akan menguntungkan atau merugikan anda. Anda perlu melengkapi dan menandatangani lembar informasi dan lembar pelepasan hasil visual dalam

penelitian ini jika anda setuju ikut serta dalam penelitian ini. Anda bisa mengundurkan diri dari penelitian ini kapan saja. Jika anda memilih untuk mengundurkan diri dari studi ini, kemudian anda akan ditawarkan pilihan untuk memiliki hasil wawancara ini atau mengizinkan saya menggunakan hasil wawancara ini. Namun, ketika hasil penelitian ini sudah dianalisa lebih lanjut, penghapusan data terkait anda kemungkinan sangat sulit untuk dilakukan.

Apa yang akan terjadi dalam penelitian ini?

Satu atau lebih dari satu pertemuan informal akan dilakukan selama penelitian ini. Anda dan saya akan mengatur tempat dan waktu pertemuan informal kita. Anda akan dijelaskan proses penelitian termasuk (jika anda tidak keberatan) berbagi foto, kliping (kumpulan gambar, koran, majalah, tulisan anda dsb), dan/atau menggambar atau membuat peta pikiran atau metode seni ala Palembang seperti Pantun selama wawancara. Beberapa topik terkait tujuan penelitian, termasuk pengetahuan tentang PPIA, kendala akses PPIA, faktor yang bisa mengaktifkan ibu positif HIV untuk akses layanan PPIA, dan ide terkait peningkatan akses layanan PPIA.

Ketidaknyamanan dan risiko apa dalam penelitian ini?

Anda mungkin mengalami tingkat ketidaknyamanan karena saya akan mengetahui status HIV anda. Selain itu, selama wawancara, anda mungkin merasa tidak nyaman dan sedih untuk berbagi cerita tentang kehidupan anda, keibuan dan HIV, dan keluarga anda. Anda mungkin juga merasa tidak nyaman jika suami/pasangan anda mengetahui anda ikut serta dalam penelitian ini. Dan juga anda juga mungkin merasa tidak nyaman, jika teman atau saudara anda melihat anda bersama saya di area/tempat umum.

Bagaimana ketidaknyamanan dan resiko ini bisa diminimalisir?

Saya akan bersikap positif, berempati dan menjadi pendengar yang baik selama proses wawancara dan tidak akan bersikap negatif terhadap status HIV anda.

Anda mempunyai pilihan untuk tidak menjawab pertanyaan yang diajukan

Anda memiliki hak untuk menghapus semua hasil rekaman wawancara dan/atau meninggalkan penelitian kapan saja tanpa alasan.

Tempat wawancara diutamakan di tempat yang memiliki tempat tertutup, seperti kantor LSM, jika memungkinkan, tetapi jika tidak, saya akan mengganti kata HIV menjadi nama penyakit lain, misalnya sakit gigi selama wawancara

Jika diminta, peneliti dan asisten peneliti akan menjelaskan penelitian ini kepada suami and jika diperlukan

Pelayanan konseling professional HIV akan disediakan, jika anda membutuhkan.

Apa manfaat penelitian ini?

Anda

Anda mungkin tidak mendapatkan manfaat penelitian ini secara langsung, namun keterlibatan anda pada studi ini, memberikan ruangan dan kesempatan untuk menyampaikan/ mengekspresikan ide, suara anda dan memilih metode apa untuk membantu anda dalam mengekspresikan ide, dan suara dan harapah melalui metode visual dalam penelitian ini berdasarkan perspektif dan konteks kehidupan anda.

Populasi yang lebih luas

Hasil penelitian ini juga bermanfaat bagi masyarakat Indonesia dan wilayah Asia tenggara karena studi ini fokus pada akses wanita pada layanan PPIA dan partisipasi wanita dalam menyampaikan dan menyuarakan ide dan aspirasi mereka untuk akses PPIA yang lebih baik pada wilayah ini. Untuk negara lainnya, terkhusus negara yang mayoritas Muslim, studi ini akan menambah pemahaman sebagai perempuan berdasarkan kehidupan agama dan sosial.

Untuk peneliti

Dengan melaksanakan penelitian ini, saya akan melengkapi persyaratan gelar S3 saya sebagai mahasiswa dan peneliti. Selain itu, pengalaman dan pengetahuan selama penelitian ini akan meningkatkan kemampuan penelitian saya dan pengetahuan saya dalam hal penelitian tindakan aktif dan pelayanan, kebijakan dan program PPIA di Indonesia.

Bagaimana kerahasiaan saya dijaga?

Sebelum memulai kegiatan pengumpulan data, anda akan diberikan dan dijelaskan informasi terkait penelitian ini. Kemudian jika anda setuju untuk ikut serta dalam penelitian ini, saya akan meminta anda untuk menandatangani form persetujuan tertulis dan form pelepasan tertulis.

Semua informasi sangat rahasia. Kode unik atau nama bukan sebenarnya akan digunakan untuk setiap partisipan pada setiap transkrip hasil interview, observation and publikasi. Saya yang hanya tahu untuk kode unik atau nama samaran. Saya juga akan membatasi akses hasil transkrip, metode visual, catatan lapangan, dan hasil penelitian lainnya hanya kepada pembimbing disertai saya.

Semua dokumen terhasil rekaman interview, dan hasil transkrip interview akan disimpan di komputer saya yang memiliki password. Hasil transkrip, lembar persetujuan, dan lembar pelepasan dokumen participant, visual outputs, catatan tangan, dan dokumen lainnya terkait penelitian akan disimpan pada lemari terkunci di kantor supervisor saya di Jurusan Kesehatan Masyarakat dan Psikososial, di Universitas Auckland Teknologi dengan maksimal penyimpanan 6 tahun dari selesainya proyek penelitian ini.

Apa yang anda dapatkan sebagai kompensasi dalam penelitian ini?

Makanan ringan dan/atau makan siang bersama serta voucher transportasi akan disediakan, dan koha atau hadiah akan diberikan pada pertemuan terakhir penelitian ini di lapangan.

Berapa lamakah waktu saya untuk menjawab undangan ini?

Anda diberikan waktu hingga dua minggu untuk memutuskan apakah anda bersedia berpartisipasi dalam penelitian ini. Anda bisa mengirim sms atau email jika ingin bertanya lebih lanjut terkait penelitian ini.

Bagaimana saya akan menerima umpan balik atas penelitian ini?

Leaflet singkat terkait hasil kesimpulan penelitian akan diinformasikan kepada anda dimasa depan melalui kelompok sebaya pada LSM terkait HIV atau Dinas Kesehatan Kota Palembang.

Bagaimana jika saya mempunyai kekhawatiran tentang penelitian ini?

Jika anda memiliki kekhawatiran terhadap penelitian ini, silahkan menghubungi pembimbing disertai saya Dr Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

Dengan siapa saya akan hubungi untuk informasi lanjut penelitian ini?

Silahkan simpan lembar informasi ini dan Salinan dari lembar persetujuan anda untuk keperluan referensi di masa akan datang. Untuk informasi lebih lanjut, silahkan hubungi

Kontak lengkap peneliti

Najmah, najem240783@gmail.com, +6285267412242 (Indonesia), +64 226460427 (Auckland)

Kontak detail pembimbing disertasi:

Sari Andajani, sari.andajani@aut.ac.nz,

Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

**Disetujui oleh Komite Etik Universitas Auckland Teknologi pada tanggal 7 Maret 2017
dengan nomor referensi AUTEK 17/22**

B.a.5: (English) For focus group discussion with key informants

PARTICIPANT INFORMATION SHEET

Date Information Sheet Produced: 31 January 2017

Project Title

Enabling HIV-positive women of childbearing age to access Prevention of Mother-to-Child Transmission (PMTCT) Services in Indonesia

An Invitation

Assalamu'alaikum warohmatullahiwabarokatuh

Hi, I am Najmah, a Ph.D. student in the school of Public Health and Psychosocial Studies, Auckland University of Technology, New Zealand. I am also a mother of two children and stay in Palembang. I would like to invite you to participate in my study. This study is a requirement of my doctoral degree.

I will be the primary researcher of this study. My supervisors are Dr. Sari Andajani and Assoc. Prof. Sharyn Graham Davies.

Your participant is voluntary (your choice). You can withdraw or leave this study at any time prior to completion of data collection and without giving me any explanation.

What is the purpose of this research?

The aim of this study is to create a space for positive-HIV mothers' ideas and aspirations to enable them to access PMTCT services. Research questions in this study are: 1) what factors enable HIV-positive women to access PMTCT services?; 2) What are the best strategies for enabling HIV-positive women to access PMTCT services?; and 3) How are these strategies implemented?

In the future, I will present the result of this study in my Ph.D. dissertation and seminars related to the topic. In addition, I intend to publish outputs of my research project in journals, a conference paper or other academic publications or presentations.

How was I identified and why am I being invited to participate in this research?

Any initial contact with you will be obtained from the researcher's informal or formal approaches to existing networks of HIV stakeholders and NGOs related to HIV.

How do I agree to participate in this research?

You will be given up to two weeks to consider joining this study. Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You will resend the confirmation form related to your attendance in a focus group discussion through my email address or text me about your attendance.

What will happen in this research?

One to two focus group discussions will be conducted during this study. The schedules and places of meeting will be arranged by group consensus at an informal meeting place, for instance the NGO office and/or meeting room in health office. Your responses and thoughts related to the

voices, ideas and aspirations from previous focus group discussions with HIV-positive women of childbearing age will be explored, including, the understanding about PMTCT services, barriers or lack of accessibility of PMTCT services, factors to activate HIV-positive mothers to access PMTCT services, and ideas related to the enhancement of the accessibility of PMTCT services. A group activity will be combined with one or two of the following visual methods, like drawings, mind-mapping and a collage or traditional oral expression like poems.

What are the discomforts and risks?

You might experience a level of discomfort because some of the key informants might have a higher position than you in your office or among HIV stakeholders

How will these discomforts and risks be alleviated?

I will try to form a homogenous membership of each group discussion, representing each particular participant

What are the benefits?

Participants

It is hoped that you might learn how to access and consider grass-root voices, ideas, and aspirations and how to bridge the thoughts of HIV-positive women of childbearing age into the real practice of PMTCT services during group discussion.

Benefits of this research to wider Indonesian community and those in the South-East Asian region

Findings from this research is of benefit to the wider Indonesian community and the South-East Asian region as a case study concerning women's access to PMTCT services, and women's participation in voicing their ideas and aspirations for better access of PMTCT services in the region. For other countries that are predominantly Muslim, it is anticipated that women might reflect their concern within their religious or social context.

Benefits of this research to the researcher

This field research is contributing to the completion of a doctoral study of Najmah. Experiences and knowledge gained from this research will enhance the primary researcher's skills and knowledge in participatory action research and her future work within PMTCT services, policies, and programmes in Indonesia.

How will my privacy be protected?

Before starting any data collection, you will be given, and explained, the information sheet related to this study. Then, if you agree to get involved, I will ask you to sign a written informed consent and release form.

All information will be strictly confidential. A unique code or a pseudonym name will be assigned for each participant in each transcript of the focus group discussion or publications. I am the only person who will know details of your unique code or pseudonym name. I also will limit the accessibility of transcript, visual methods, field notes and other research outcomes to only my supervisors and myself, as primary researcher.

Group discussion recordings and transcripts will be stored in my locked computer files. All documents related to this research, including transcript results, consent form, release form, visual

output, and field notes and other outputs will be stored in a locked cabinet at my supervisor's office at the School of Public Health and Psychosocial Studies, and Department of Social Science, Auckland University of Technology, New Zealand for at least six years.

What are the costs of participating in this research?

Refreshment and/or lunch will be provided for participants. A transportation voucher will be provided at each meeting, and a koha or gift will be provided at the end of the study.

What opportunity do I have to consider this invitation?

You will be given up to two weeks to decide if you wish to take part in this study. You can send me a confirmation form by email or text me your availability or to ask any questions or clarify any further information regarding the research.

Will I receive feedback on the results of this research?

A short leaflet containing the research findings will be shared with you in the future through your institution.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified to the Project Supervisor, Dr Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, Kate O'Connor, ethics@aut.ac.nz, +64 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Najmah, najem240783@gmail.com, +6285267412242 (Indonesia), +64 226460427 (Auckland)

Project Supervisor Contact Details:

Sari Andajani, sari.andajani@aut.ac.nz,

Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

Any concerns regarding the nature of this project should be notified to the Project Supervisor, Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

**Approved by the Auckland University of Technology Ethics Committee on 7 Maret 2017,
AUTECH Reference number 17/22**

B.a.6: (Indonesian) Untuk diskusi kelompok terarah untuk informan kunci

LEMBAR INFORMASI UNTUK PESERTA PENELITIAN

Tanggal lembar informasi dibuat :

31 Januari 2017

Judul Projek Penelitian

Memampukan ibu positif HIV usia subur untuk mengakses layanan pencegahan penularan HIV dari ibu ke anak (PPIA) di Indonesia

Undangan

Assalamu'alaikum warohmatullahiwabarokatuh

Hi, saya Najmah, mahasiswa S3 dari Jurusan Kesehatan Masyarakat dan Psykososial di Universitas Teknologi Auckland, Selandia Baru. Saya bermaksud mengundang anda untuk berpartisipasi dalam penelitian ini. Penelitiain ini merupakan syarat dalam proses S3 saya.

Saya adalah peneliti utama pada penelitian ini. Pembimbing disertasi saya adalah Sari Andajani dan Sharyn Graham Davies.

Partisipasi anda adalah sukarela. Anda bisa mengundurkan diri atau meninggalkan penelitian ini kapan saja tanpa harus mengikuti hingga pengumpulan data selesai dan tanpa memberikan penjelasan apapun kepada saya.

Apa tujuan penelitian ini?

Tujuan dari penelitian ini adalah untuk memberikan ruang bagi ibu positif HIV untuk memampukan mereka untuk mengakses layanan Pencegahan Penularan HIV dari Ibu ke anak. Pertanyaan penelitian saya adalah 1) faktor apa saja yang mengaktifkan ibu positif HIV untuk mengakses layanan PPIA? 2) Bagaimana ibu positif HIV bisa difasilitasi untuk mengembangkan strategi untuk cara terbaik akses layanan PPIA? Dan 3) bagaimana strategi ini bisa direalisasikan?

Kebanyakan kasus bayi HIV baru terinfeksi HIV dari ibu yang positif HIV selama kehamilan, proses melahirkan dan menyusui. Ada program pelayanan pencegahan penularan dari Ibu ke anak (PPIA) menawarkan dapat mencegah penularan HIV dari ibu ke anak hingga kurang dari 5 % (mayoritas anak dari ibu HIV dapat bebas dari HIV) jika perempuan positif HIV akses pengobatan komprehensif antiretroviral di pelayanan PPIA. Walaupun demikian, hanya sekitar 8-10 % ibu positif HIV dan ibu hamil yang positif HIV yang akses pelayanan PPIA di Indonesia.

Dimasa yang akan datang, saya akan mempresentasikan hasil studi penelitian ini dalam disertasi S3, dan seminar terkait topik penelitian ini. Saya juga akan berencana akan mempublikasikan hasil penelitian ini ke jurnal, artikel prosiding seminar atau kegiatan akamedik lainnya.

Bagaimana saya diidentifikasi dan bagaimana saya diundang untuk berpartisipasi dalam penelitian ini?

Kontak awal dengan anda diperoleh dari jaringan kerja peneliti baik formal maupun tidak formal terhadap lembaga pemerintah dan lembaga swadaya masyarakat terkait HIV.

Bagaimana saya menyatakan keikutsertaan (setuju) untuk berpartisipasi dalam penelitian ini?

Anda diberikan hingga dua minggu untuk mempertimbangkan mengikuti penelitian ini. Partisipasi anda adalah sukarela (pilihan anda) dan apakah anda memilih untuk berpartisipasi atau tidak dimana menurut anda akan menguntungkan atau merugikan anda. Anda perlu melengkapi dan menandatangani lembar kesediaan untuk mengikuti diskusi kelompok terarah lewat email atau melalui pesan singkat.

Apa yang akan terjadi dalam penelitian ini?

Satu atau dua diskusi kelompok terarah akan dilakukan selama penelitian ini. Tempat diskusi akan ditentukan sesuai ketersediaan ruangan rapat pada salah satu lembaga terkait HIV atau tempat kerja peneliti atau tempat yang menyediakan ruangan pertemuan khusus, seperti di rumah makan atau hotel. Tanggapan dan ide anda terhadap suara, ide dan aspirasi ibu positif HIV dari kegiatan diskusi terarah dengan mereka akan di diskusikan bersama, termasuk pemahaman mereka tentang PPIA, kendala dalam mengakses PPIA, faktor faktor yang bisa memotivasi mereka untuk akses ke PPIA dan ide bagaimana meningkatkan daya akses mereka terhadap PPIA. Kegiatan ini akan dikombinasi dengan metode visul, seperti menggambar, peta pikiran dan koalase atau klipping atau juga melalui pantun dan cara tradisional Palembang lainnya.

Ketidaknyamanan dan risiko apa dalam penelitian ini?

Anda mungkin merasa tidak nyaman karena beberapa informan kunci mungkin memiliki posisi yang lebih tinggi di kantor anda atau diantara lembaga terkait HIV.

Bagaimana ketidaknyamanan dan resiko ini bisa diminimalisir?

Saya akan berusaha membantu kelompok yang memiliki karakteristik atau posisi yang hampir sama pada setiap kelompok diskusi

Apa manfaat penelitian ini?

Anda

Anda mungkin akan belajar bagaimana memahami suara, ide dan aspirasi dari kelompok pengguna pelayanan atau grass-root dan menjembatani ide mereka ke implementasi layanan PPIA pada diskusi kelompok

Populasi yang lebih luas

Hasil penelitian ini juga bermanfaat bagi masyarakat Indonesia dan wilayah Asia tenggara karena studi ini fokus pada akses wanita pada layanan PPIA dan partisipasi wanita dalam menyampaikan dan menyuarakan ide dan aspirasi mereka untuk akses PPIA yang lebih baik pada wilayah ini. Untuk negara lainnya, terkhusus negara yang mayoritas Muslim, studi ini akan menambah pemahaman sebagai perempuan berdasarkan kehidupan agama dan sosial.

Untuk peneliti

Dengan melaksanakan penelitian ini, saya akan melengkapi persyaratan gelar S3 saya sebagai mahasiswa dan peneliti. Selain itu, pengalaman dan pengetahuan selama penelitian ini akan meningkatkan kemampuan penelitian saya dan pengetahuan saya dalam hal penelitian tindakan aktif dan pelayanan, kebijakan dan program PPIA di Indonesia.

Bagaimana kerahasiaan saya dijaga?

Sebelum memulai kegiatan pengumpulan data, anda akan diberikan dan dijelaskan informasi terkait penelitian ini. Kemudian jika anda setuju untuk ikut serta dalam penelitian ini, saya akan meminta anda untuk menandatangani form persetujuan tertulis dan form pelepasan tertulis.

Semua informasi sangat rahasia. Kode unik atau nama bukan sebenarnya akan digunakan untuk setiap partisipan pada setiap transkrip hasil diskusi, observation and publikasi. Saya yang hanya tahu untuk kode

unik atau nama samaran. Saya juga akan membatasi akses hasil transkrip, metode visual, catatan lapangan, dan hasil penelitian lainnya hanya kepada pembimbing disertasi saya.

Semua dokumen terhasil rekaman diskusi, dan hasil transkrip diskusi akan disimpan di komputer saya yang memiliki password. Hasil transkrip, lembar persetujuan, dan lembar pelepasan dokumen participant, visual outputs, catatan tangan, dan dokumen lainnya terkait penelitian akan disimpan pada lemari terkunci di kantor supervisor saya di Jurusan Kesehatan Masyarakat dan Psikososial, dan Departmenet Ilmu Sosial di Universitas Auckland Teknologi dengan maksimal penyimpanan 6 tahun dari selesainya proyek penelitian ini.

Apa yang anda dapatkan sebagai kompensasi dalam penelitian ini?

Makanan ringan dan/atau makan siang bersama serta voucer transportasi akan disediakan, dan koha atau hadiah akan diberikan pada pertemuan terakhir penelitian ini di lapangan.

Berapa lamakah waktu saya untuk menjawab undangan ini?

Anda diberikan waktu selama satu hingga dua minggu untuk memutuskan apakah anda bersedia berpartisipasi dalam penelitian ini. Anda bisa mengirim sms atau email jika ingin bertanya lebih lanjut terkait penelitian ini.

Bagaimana saya akan menerima umpan balik atas penelitian ini?

Leaflet singkat terkait hasil kesimpulan penelitian akan dikirimkan pada institusi anda bekerja

Bagaimana jika saya mempunyai kekhawatiran tentang penelitian ini?

Jika anda memiliki kekhawatiran terhadap penelitian ini, silahkan menghubungi pembimbing disertasi saya Dr Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

Kekhawatiran terkait pelaksanaan penelitian dapat disampaikan pada sekretaris eksekutif dari AUTEK, Kate O'Connor, ethics@aut.ac.nz, +64 921 9999 ext 6038.

Dengan siapa saya akan hubungi untuk informasi lanjut penelitian ini?

Silahkan simpan lembar informasi ini dan Salinan dari lembar persetujuan anda untuk keperluan referensi di masa akan datang. Untuk informasi lebih lanjut, silahkan hubungi

Kontak lengkap peneliti

Najmah di no hp +62 85267412242 atau email najem240783@yahoo.com

Kontak detail pembimbing disertasi:

Sari Andajani, sari.andajani@aut.ac.nz,

Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

Ada pertanyaan lebih lanjut hubungi, Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999
ext. 7738

**Disetujui oleh Komite Etik Universitas Auckland Teknologi pada tanggal 7 Maret 2017
dengan nomor referensi AUTEK 17/22**

B.a.7: (English) For interviews with key informants

PARTICIPANT INFORMATION SHEET

Date Information Sheet Produced:

31 January 2017

Project Title

Enabling HIV-positive women of childbearing age to access Prevention of Mother-to-Child Transmission (PMTCT) services in Indonesia

An Invitation

Assalamu'alaikum warohmatullahiwarokatuh

Hi, I am Najmah, a Ph.D. student in the school of Public Health and Psychosocial Studies, Auckland University of Technology, New Zealand. I am also a mother of two children and stay in Palembang. I would like to invite you to participate in my study. This study is a requirement of my doctoral degree.

I will be the primary researcher of this study. My supervisors are Dr. Sari Andajani and Assoc. Prof. Sharyn Graham Davies.

Your participant is voluntary (your choice). You can withdraw or leave this study at any time prior to completion of data collection and without giving me any explanation.

What is the purpose of this research?

The aim of this study is to create a space for positive-HIV mothers' ideas and aspirations to enable them to access PMTCT services. Research questions in this study are: 1) what factors enable HIV-positive women to access PMTCT services?; 2) What are the best strategies for enabling HIV-positive women to access PMTCT services?; and 3) How are these strategies implemented?

In the future, I will present the result of this study in my Ph.D. dissertation and seminars related to the topic. In addition, I intend to publish outputs of my research project in journals, a conference paper or other academic publications or presentations.

How was I identified and why am I being invited to participate in this research?

Any initial contact with you will be obtained from the researcher's in formal or formal approaches to existing networks of HIV stakeholders and NGOs related to HIV.

How do I agree to participate in this research?

You will be given up to two weeks to consider joining this study. Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You will be offered a one to one meeting with the primary researcher.

What will happen in this research?

One or two informal meetings will be performed during this study. The schedules and places of the meetings will be arranged by you. Your responses and thoughts related to the voices, ideas, and aspirations from previous focus group discussions with HIV-positive women of childbearing age will be explored, including, the understanding about PMTCT services, barriers or lack of accessibility to PMTCT services, factors that activate HIV-positive mothers to access PMTCT services, and ideas related to the enhancement of the accessibility of PMTCT services. An interview activity will be combined with one or two of the following visual methods, like drawings, mind-mapping, and a collage or traditional oral expression like poems.

What are the discomforts and risks?

N/A

How will these discomforts and risks be alleviated?

N/A

What are the benefits?

Participants

It is hoped that you might learn how to access and consider grass-root voices, ideas, and aspirations, and how to bridge the thoughts of HIV-positive women of childbearing age into the real practice of PMTCT services during group discussion and/or interview.

Benefits of this research to wider Indonesian community and those in the South-East Asian region

Findings from this research are of benefit to the wider Indonesian community and South-East Asian region as a case study concerning women's access to PMTCT services, and women's participation in voicing their ideas and aspirations for better access of PMTCT services in the region. For other countries, that are predominantly Muslim, it is anticipated that women might reflect their concern within their religious or social context.

Benefits of this research to the researcher

This field research is contributing to the completion of a doctoral study. Experiences and knowledge gained from this research will enhance the primary researcher's skills and knowledge in participatory action research and her future work within PMTCT services, policies, and programmes in Indonesia.

How will my privacy be protected?

Before starting any data collection, you will be given, and explained, the information sheet related to this study. Then, if you agree to get involved, I will ask you to sign a written informed consent and release consent form.

All information will be strictly confidential. A unique code or a pseudonym name will be assigned to each participant in each transcript of the interview or publications. I am the only person who will know details of a unique code or pseudonym names. I also will limit the accessibility of transcript, visual methods, field notes and other research outcomes to my supervisors and myself, as primary researcher.

Interview recordings and transcripts will be stored in my locked computer files. All documents related to this research, including transcript results, consent form, release form, visual output,

field and reflection notes and other traditional oral expressions will be stored in a locked cabinet at my supervisor's office at the School of Public health and Psychosocial Studies and Department of Social Science, Auckland University of Technology, New Zealand for at least six years.

What are the costs of participating in this research?

Refreshment and/or lunch will be provided for participants. A transportation voucher will be provided at each meeting, and a koha or gift will be provided at the end of the study.

What opportunity do I have to consider this invitation?

You will be given up to two weeks to decide taking part in this study. You can send me a confirmation form by email or just text me your availability or to ask any questions or clarify any further information regarding the research.

Will I receive feedback on the results of this research?

A short leaflet containing the research findings will be shared with you in the future through your institution.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified to the Project Supervisor, Dr Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, +64 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Najmah, najem240783@gmail.com, +6285267412242, +64 226460427

Project Supervisor Contact Details:

Sari Andajani, sari.andajani@aut.ac.nz,

Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

**Approved by the Auckland University of Technology Ethics Committee on 7 March 2017,
AUTEK Reference number 17/22**

B.a.8: (Indonesian) Untuk interview untuk informan kunci

LEMBAR INFORMASI UNTUK PESERTA PENELITIAN

Tanggal lembar informasi dibuat :

31 Januari 2017

Judul Projek Penelitian

Memampukan ibu positif HIV usia subur untuk mengakses layanan pencegahan penularan HIV dari ibu ke anak (PPIA) di Indonesia

Undangan

Assalamu'alaikum warohmatullahiwarokatuh

Hi, saya Najmah, mahasiswa S3 dari Jurusan Kesehatan Masyarakat dan Psykososial di Universitas Teknologi Auckland, Selandia Baru. Saya bermaksud mengundang anda untuk berpartisipasi dalam penelitian ini. Penelitiain ini merupakan syarat dalam proses S3 saya.

Saya adalah peneliti utama pada penelitian ini. Pembimbing disertasi saya adalah Sari Andajani dan Sharyn Graham Davies.

Partisipasi anda adalah sukarela. Anda bisa mengundurkan diri atau meninggalkan penelitian ini kapan saja tanpa harus mengikuti hingga pengumpulan data selesai dan tanpa memberikan penjelasan apapun kepada saya.

Apa tujuan penelitian ini?

Tujuan dari penelitian ini adalah untuk memberikan ruang bagi ibu positif HIV untuk memampukan mereka untuk mengakses layanan Pencegahan Penularan HIV dari Ibu ke anak. Pertanyaan penelitian saya adalah 1) faktor apa saja yang mengaktifkan ibu positif HIV untuk mengakses layanan PPIA? 2) Bagaimana ibu positif HIV bisa difasilitasi untuk mengembangkan strategi untuk cara terbaik akses layanan PPIA? Dan 3) bagaimana strategi ini bisa direalisasikan?

Kebanyakan kasus bayi HIV baru terinfeksi HIV dari ibu yang positif HIV selama kehamilan, proses melahirkan dan menyusui. Ada program pelayanan pencegahan penularan dari Ibu ke anak (PPIA) menawarkan dapat mencegah penularan HIV dari ibu ke anak hingga kurang dari 5 % (mayoritas anak dari ibu HIV dapat bebas dari HIV) jika perempuan positif HIV akses pengobatan komprehensif antiretroviral di pelayanan PPIA. Walaupun demikian, hanya sekitar 8-10 % ibu positif HIV dan ibu hamil yang positif HIV yang akses pelayanan PPIA di Indonesia.

Dimasa yang akan datang, saya akan mempresentasikan hasil studi penelitian ini dalam disertasi S3, dan seminar terkait topik penelitian ini. Saya juga akan berencana akan mempublikasikan hasil penelitian ini ke jurnal, artikel prosiding seminar atau kegiatan akamedik lainnya.

Bagaimana saya diidentifikasi dan bagaimana saya diundang untuk berpartisipasi dalam penelitian ini?

Kontak awal dengan anda diperoleh dari jaringan kerja peneliti baik formal maupun tidak formal terhadap lembaga pemerintah dan lembaga swadaya masyarakat terkait HIV.

Bagaimana saya menyatakan keikutsertaan (setuju) untuk berpartisipasi dalam penelitian ini?

Anda diberikan hingga dua minggu untuk mempertimbangkan mengikuti penelitian ini. Partisipasi anda adalah sukarela (pilihan anda) dan apakah anda memilih untuk berpartisipasi atau tidak dimana menurut anda akan menguntungkan atau merugikan anda. Anda perlu melengkapi dan menandatangani lembar kesediaan untuk mengikuti wawancara lewat email atau melalui pesan singkat.

Apa yang akan terjadi dalam penelitian ini?

Satu atau dua pertemuan wawancara akan dilakukan selama penelitian ini. Tempat wawancara akan ditentukan sesuai ketersediaan ruangan rapat pada salah satu lembaga terkait HIV atau tempat kerja peneliti atau tempat yang menyediakan ruangan pertemuan khusus, seperti di rumah makan atau hotel. Tanggapan dan ide anda terhadap suara, ide dan aspirasi ibu positif HIV dari kegiatan diskusi terarah dengan mereka akan di diskusikan bersama, termasuk pemahaman mereka tentang PPIA, kendala dalam mengakses PPIA, faktor faktor yang bisa memotivasi mereka untuk akses ke PPIA dan ide bagaimana meningkatkan daya akses mereka terhadap PPIA. Kegiatan ini akan dikombinasi dengan metode visual, seperti menggambar, peta pikiran dan koalase atau klipping atau juga melalui pantun dan cara tradisional Palembang lainnya.

Ketidaknyamanan dan risiko apa dalam penelitian ini?

N/A

Bagaimana ketidaknyamanan dan resiko ini bisa diminimalisir?

N/A

Apa manfaat penelitian ini?

Anda

Anda mungkin akan belajar bagaimana memahami suara, ide dan aspirasi dari kelompok pengguna pelayanan atau grass-root dan menjembatani ide mereka ke implementasi layanan PPIA pada diskusi kelompok

Populasi yang lebih luas

Hasil penelitian ini juga bermanfaat bagi masyarakat Indonesia dan wilayah Asia tenggara karena studi ini fokus pada akses wanita pada layanan PPIA dan partisipasi wanita dalam menyampaikan dan menyuarakan ide dan aspirasi mereka untuk akses PPIA yang lebih baik pada wilayah ini. Untuk negara lainnya, terkhusus negara yang mayoritas Muslim, studi ini akan menambah pemahaman sebagai perempuan berdasarkan kehidupan agama dan sosial.

Untuk peneliti

Dengan melaksanakan penelitian ini, saya akan melengkapi persyaratan gelar S3 saya sebagai mahasiswa dan peneliti. Selain itu, pengalaman dan pengetahuan selama penelitian ini akan meningkatkan kemampuan penelitian saya dan pengetahuan saya dalam hal penelitian tindakan aktif dan pelayanan, kebijakan dan program PPIA di Indonesia.

Bagaimana kerahasiaan saya dijaga?

Sebelum memulai kegiatan pengumpulan data, anda akan diberikan dan dijelaskan informasi terkait penelitian ini. Kemudian jika anda setuju untuk ikut serta dalam penelitian ini, saya akan meminta anda untuk menandatangani form persetujuan tertulis dan form pelepasan tertulis.

Semua informasi sangat rahasia. Kode unik atau nama bukan sebenarnya akan digunakan untuk setiap partisipan pada setiap transkrip hasil interview, observation and publikasi. Saya yang hanya tahu untuk kode

unik atau nama samaran. Saya juga akan membatasi akses hasil transkrip, metode visual, catatan lapangan, dan hasil penelitian lainnya hanya kepada pembimbing disertasi saya.

Semua dokumen terhasil rekaman diskusi, dan hasil transkrip interview akan disimpan di komputer saya yang memiliki password. Hasil transkrip, lembar persetujuan, dan lembar pelepasan dokumen participant, visual outputs, catatan tangan, dan dokumen lainnya terkait penelitian akan disimpan pada lemari terkunci di kantor supervisor saya di Jurusan Kesehatan Masyarakat dan Psikososial, di Universitas Auckland Teknologi dengan maksimal penyimpanan 6 tahun dari selesainya proyek penelitian ini.

Apa yang anda dapatkan sebagai kompensasi dalam penelitian ini?

Makanan ringan dan/atau makan siang bersama serta voucher transportasi akan disediakan, dan koha atau hadiah akan diberikan pada pertemuan terakhir penelitian ini di lapangan.

Berapa lamakah waktu saya untuk menjawab undangan ini?

Anda diberikan waktu selama satu hingga dua minggu untuk memutuskan apakah anda bersedia berpartisipasi dalam penelitian ini. Anda bisa mengirim sms atau email jika ingin bertanya lebih lanjut terkait penelitian ini.

Bagaimana saya akan menerima umpan balik atas penelitian ini?

Leaflet singkat terkait hasil kesimpulan penelitian akan dikirimkan pada institusi anda bekerja

Bagaimana jika saya mempunyai kekhawatiran tentang penelitian ini?

Jika anda memiliki kekhawatiran terhadap penelitian ini, silahkan menghubungi pembimbing disertasi saya Dr Sari Andajani, sari.andajani@aut.ac.nz +64 9 921 9999 ext. 7738

Kekhawatiran terkait pelaksanaan penelitian dapat disampaikan pada sekretaris eksekutif dari AUTEK, Kate O'Connor, ethics@aut.ac.nz, +64 9 21 9999 ext 6038.

Dengan siapa saya akan hubungi untuk informasi lanjut penelitian ini?

Silahkan simpan lembar informasi ini dan Salinan dari lembar persetujuan anda untuk keperluan referensi di masa akan datang. Untuk informasi lebih lanjut, silahkan hubungi

Kontak lengkap peneliti

Najmah di no hp +62 85267412242 atau email najem240783@yahoo.com

Kontak detail pembimbing disertasi:

Sari Andajani, sari.andajani@aut.ac.nz, Sharyn Graham Davies, Sharyn.davies@aut.ac.nz

**Disetujui oleh Komite Etik Universitas Auckland Teknologi pada tanggal 7 Maret 2017
dengan nomor referensi AUTEK 17/2**

Appendix B.b: Consent forms

B.b.1: (English) Consent form for image recording

For use when photographs, videos or other image recording is being used

Project title: Enabling HIV-positive women of childbearing age to access Prevention of Mother-to-Child Transmission (PMTCT) services in Indonesia

Project Supervisor: Dr. Sari Andajani & Assoc. Prof. Sharyn Graham Davies

Researcher: Najmah, SKM, MPH

- I have read and understood the information provided about this research project in the Information Sheet dated dd mm yyyy.
- I have had an opportunity to ask questions and to have them answered.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I permit the researcher to use the photographs that are part of this project and/or any drawings from them and any other reproductions or adaptations from them, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for (a) the researcher's portfolio; and (b) educational exhibition and examination purposes and related design works;
- I understand that the photographs will be used for academic purposes only will not be published in any form outside of this project without my written permission.
- I understand that any copyright material created by the photographic sessions is deemed to be owned by the researcher and that I do not own copyright of any of the photographs.
- I agree to take part in this research.

Participant's signature :.....

Participant's name :.....

Participant's Contact Details (if appropriate) :.....

Date:

*Approved by the Auckland University of Technology Ethics Committee on 7 March 2017
AUTEK Reference number 17/22*

B.b.2: (Indonesian) Formulir Persetujuan dan Pelepasan

Untuk digunakan ketika foto, video atau gambar lainnya digunakan

Judul Penelitian:

Memampukan ibu positif HIV usia subur untuk mengakses layanan pencegahan penularan HIV dari ibu ke anak (PPIA) di Indonesia

Pembimbing Disertasi : **Dr Sari Andajani & Assoc Prof Sharyn Graham Davies**

Peneliti : **Najmah, SKM, MPH**

- Saya mengerti dan paham tentang informasi yang diberikan pada projek penelitian ini dalam lembar informasi tertanggal.....(tanggal)/.....(bulan)/.....(tahun)
- Saya telah diberikan kesempatan untuk bertanya dan meminta jawaban dari mereka
- Saya mengerti bahwa saya ikut serta dalam penelitian ini dengan sukarela dan saya bisa mengundurkan diri kapan saja tanpa dirugikan dengan cara apapun
- Saya mengerti bahwa saya bisa mengundurkan diri dari penelitian ini kemudian saya akan ditawarkan pilihan antara data yang telah dikumpulkan akan dihapus atau diperbolehkan untuk digunakan. Walaupun demikian, ketika hasil penelitian telah diselesaikan, penghapusan data kemungkinan tidak dapat dilakukan
- Saya mengizinkan peneliti/ahli seni untuk menggunakan foto yang menjadi bagian dari projek ini/atau gambar dari mereka dan output apapun dari mereka, baik yang mengikuti penelitian sebagian atau keseluruhan, sendiri atau menjadi bagian dari diskusi dan/atau gambar sendiri untuk (a)menjadi bagian portfolio peneliti ; dan (b) pameran pendidikan dan tujuan ujian dan berkaitan dengan pekerjaan desain.
- Saya mengerti bahwa foto akan digunakan hanya untuk tujuan akademik dan tidak akan dipublikasikan diluar projek penelitian ini tanpa izin tertulis
- Saya mengerti bahwa hak cipta dari setiap output pada sesi dokumentasi/pemotretan dimiliki oleh peneliti dan saya tidak memiliki hak cipta dari foto apapun.
- Saya setuju menjadi bagian dalam penelitian ini

Tanda tangan informan/partisipan

.....

Nama informan/partisipan

.....

Kontak person (jika diperbolehkan)

.....

Tanggal :

B.b.3: (English) Consent form for interviews

Project title: Enabling HIV-positive women of childbearing age to access Prevention of Mother-to-Child Transmission (PMTCT) services in Indonesia

Project Supervisor: Dr. Sari Andajani & Assoc. Prof. Sharyn Graham Davies

Researcher: Najmah, SKM, MPH

-
- I have read and understood the information provided about this research project in the Information Sheet dated dd mm yyyy
 - I have had an opportunity to ask questions and to have them answered
 - I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
 - I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way
 - I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
 - I agree to take part in this research
 - I wish to receive a summary of the research findings (please tick one): Yes No

Participant's signature :.....

Participant's name :.....

Participant's Contact Details (if appropriate)
:.....

Date :

**Approved by the Auckland University of Technology Ethics Committee on 7 March 2017,
AUTEK Reference number 17/22**

Note: The Participant should retain a copy of this form

B.b.4: (Indonesian) Lembar persetujuan

Untuk digunakan pada kegiatan interview

Judul Penelitian:

Memampukan ibu positif HIV usia subur untuk mengakses layanan pencegahan penularan HIV dari ibu ke anak (PPIA) di IndonesiaPembimbing Disertas : **Dr. Sari Andajani & Assoc. Prof. Sharyn Graham Davies**Peneliti : **Najmah, SKM, MPH**

- Saya mengerti dan paham tentang informasi yang diberikan pada proyek penelitian ini dalam lembar informasi tertanggal.....(tanggal)/.....(bulan)/.....(tahun)
- Saya telah diberikan kesempatan untuk bertanya dan meminta jawaban dari mereka
- Saya paham bahwa selama interview akan dicatat, direkam dan akan ditranskrip hasil rekaman
- Saya mengerti bahwa saya ikut serta dalam penelitian ini dengan sukarela dan saya bisa mengundurkan diri kapan saja tanpa dirugikan dengan cara apapun
- Saya mengerti bahwa saya bisa mengundurkan diri dari penelitian ini kemudian saya akan ditawarkan pilihan antara data yang telah dikumpulkan akan dihapus atau diperbolehkan untuk digunakan. Walaupun demikian, ketika hasil penelitian telah diselesaikan, penghapusan data kemungkinan tidak dapat dilakukan
- Saya setuju ikut serta dalam penelitian ini
- Saya berharap bisa menerima kesimpulan dari data penelitian ini : Ya Tidak

Tanda tangan informan/partisipan
:.....Nama informan/partisipan
:.....

Kontak person (jika diperbolehkan) :.....

Tanggal :

Disetujui oleh Komite Etik Universitas Teknologi Auckland pada 7 Maret 2017.dengan nomor referensi AUTEK 17/22

Catatan: Partisipan harus memegang kopi dari formulir ini

B.b.5: (English) Consent form for focus groups

For use when focus groups are involved.

Project title: Enabling HIV-positive women of childbearing age to access Prevention of Mother-to-Child Transmission (PMTCT) services in Indonesia

Project Supervisor: Dr. Sari Andajani & Assoc. Prof. Sharyn Graham Davies

Researcher: Najmah, SKM, MPH

- I have read and understood the information provided about this research project in the Information Sheet dated (dd mm yyyy)
- I have had an opportunity to ask questions and to have them answered
- I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential
- I understand that notes will be taken during the focus group and that it will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then, while it may not be possible to destroy all records of the focus group discussion of which I was part, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): Yes No

Participant's signature :.....

Participant's name :.....

Participant's Contact Details (if appropriate)

.....

Date:

***Approved by the Auckland University of Technology Ethics Committee on 7 March 2017
AUTEK Reference number 17/22***

Note: The Participant should retain a copy of this form

B.b.6: (Indonesian) Lembar Persetujuan

Untuk digunakan diskusi group

Judul Penelitian:

Memampukan ibu positif HIV usia subur untuk mengakses layanan pencegahan penularan HIV dari ibu ke anak (PPIA) di IndonesiaPembimbing Disertasi : **Dr. Sari Andajani & Assoc. Prof. Sharyn Graham Davies**Peneliti : **Najmah, SKM, MPH**

- Saya mengerti dan paham tentang informasi yang diberikan pada projek penelitian ini dalam lembar informasi tertanggal.....(tanggal)/.....(bulan)/.....(tahun)
- Saya telah diberikan kesempatan untuk bertanya dan meminta jawaban dari mereka
- Saya mengerti identitas sesama peserta dan hasil diskusi dalam kegiatan diskusi kelompok bersifat rahasia dan saya setuju akan menjaga kerahasiaan informasi dalam kegiatan diskusi kelompok ini
- Saya paham bahwa selama diskusi kelompok akan dicatat, direkam dan hasil rekaman akan ditranskrip
- Saya mengerti bahwa saya ikut serta dalam penelitian ini dengan sukarela dan saya bisa mengundurkan diri kapan saja tanpa dirugikan dengan cara
- Saya mengerti jika saya bisa mengundurkan diri dari penelitian ini, dimana kemungkinan sangat tidak memungkinkan menghapus semua rekaman pada diskusi group dimana saya menjadi bagian dari diskusi ini, saya akan ditawarkan pilihan antara data yang teridentifikasi sebagai saya akan dihapus atau diperbolehkan untuk digunakan. Walaupun demikian, ketika hasil penelitian telah diselesaikan, penghapusan data kemungkinan tidak dapat dilakukan
- Saya setuju menjadi bagian dari penelitian ini
- Saya berharap bisa menerima rangkuman dari hasil penelitian ini: Ya Tidak

Tanda tangan informan/partisipan
:.....Nama informan/partisipan
:.....Kontak person (jika
diperbolehkan):.....

Tanggal :

Disetujui oleh Komite Etik Universitas Teknologi Auckland pada 7 March 2017 dengan nomor referensi AUTEK 17/22

Catatan: Partisipan harus memegang kopi dari formulir ini

Appendix B.c: Indicative interview and focus group discussion questions

B.c.1: Interview with HIV-positive women

(PART 1) OPENING questions

1. Do you want to share special or the best things in your life?
Probe: Do you want to share your story and show your collage/drawings/mind-mapping for you?
2. Tell me about your family?
Prompt: Tell me about your husband or child/ren? Are you living with extended family?

Note: If they do not want to share, just move to next interview questions

(Part 2) Being an HIV woman and being a mother/wife

3. Do you want to share your collage, drawings and/or another oral expression about your motherhood and HIV?
4. How has life changed after being diagnosed with HIV?
5. What are your motivations and your strengths as a mother and/or a wife?

(Part 3) Accessing prevention of mother-to-child transmission of HIV services?

6. Have you ever accessed any HIV - prevention and treatment services or programmes?
Probing: If yes, what HIV programmes? When did you access? With whom did you access?
7. Have you ever known about PMTCT services?
Probe: If yes, can you explain what do you know about PMTCT services? Would you mind to mention the programmes and when did you access the programmes?
8. Have you ever accessed PMTCT services? (If No, jump to no 9)
Probes: Please tell me more about your experience in accessing PMTCT services?; And why did you use their services? Any barriers and challenges in accessing this services? When did you access it? With whom did you access the service?
9. If no, why do you not access PMTCT services?
Probe: Barriers, challenges, etc.
10. Do you have any suggestions as to how to enable HIV-positive women to access PMTCT services?
Probe: What factors to activate HIV-positive women of childbearing age to access PMTCT services? How to enable the women to access PMTCT services? What should Mother to Child Transmission Services look like to improve the accessibility of PMTCT services?

Finally, thank you for your time. Do you have any questions that you would like to ask of me?

B.c.2: FGD with HIV-positive women

Here are some ideas of questions that may be developed with the participants during the focus group discussion:

1. Tell me what does it mean to be a mother or a wife for you?

2. If you don't mind, would you mind share any stories of yourself related to HIV, motherhood, and pregnancy?
3. Tell me what do you know about HIV prevention and treatment programmes in Palembang, South Sumatera?
4. Tell me what do you know about PMTCT services?
5. Tell me what barriers exist that prevent HIV-positive women from accessing PMTCT services?
6. Tell me what factors activate HIV-positive women to access PMTCT services?
7. Tell me ways in which to enable HIV-positive women to access PMTCT services?
8. Tell me what should Mother to Child Transmission Services look like to improve the accessibility of PMTCT services?

B.c.3: Interview and FGD with other groups (NGO, health workers and HIV policy makers)

(Part 1) Introduction and HIV programmes related to mother and children.

1. Would you mind to share your role or responsibility in your work related to HIV programmes?
2. Would you mind to share any HIV programmes related to mothers and children in Palembang city and South Sumatera Province?
3. Would you mind to share your thoughts regarding cooperation among HIV stakeholders for PMTCT programme so far?
Probing: Coordination among HIV stakeholders; challenges to the implementation of this programme; monitoring and evaluation of this programme.

(Part 2) Respond to the voices, ideas, and aspirations among HIV-positive women of childbearing age

Now we will move to ask your ideas and perspectives about accessibility of the PMTCT services based on the voices, ideas, and aspirations of HIV-positive women of childbearing age.

4. What are your perspectives or responses on their voices, ideas, and aspiration related the women's barriers to lack of accessibility of PMTCT services?
5. What are your perspectives or responses on their voices, ideas, and aspiration about factors to activate the women to access PMTCT services?
6. What are your perspectives or responses on their voices, ideas, and aspiration about the ways or strategies of enabling the women to access PMTCT services?

Notes: visual outcome or traditional oral expressions from previous discussion with HIV-positive women will be showed in this part 2.

(Part 3) Finding solutions

7. How can we bridge this information related to their ideas, thoughts, and aspirations related to how to best access PMTCT services, and to the practice of PMTCT services?
- Finally, thank you for your time. Do you have any questions that you would like to ask of me?

Notes:

More questions will be explored based on the visual productions or other traditional oral expressions in this interview.

Prepare any visual methods or other traditional oral expressions to facilitate this interview.

Appendix B.c: Letters of support

B.c.1: Permission letter from South Sumatra



PEMERINTAH PROVINSI SUMATERA SELATAN BADAN KESATUAN BANGSA DAN POLITIK

Jln. Kapten F. Tendean No. 1059 Telp/Fax. (0711) 354715 – 370030
Palembang Kode Pos 31129

REKOMENDASI PENELITIAN/SURVEI

NOMOR : 070/4/11 /Ban.KBP/2017

Kepala Badan Kesatuan Bangsa dan Politik Provinsi Sumatera Selatan memperhatikan :

- a. Dasar : 1. Peraturan Menteri Dalam Negeri Republik Indonesia Nomor 64 Tahun 2011 tentang Pedoman Penerbitan Rekomendasi Penelitian;
2. Peraturan Menteri Dalam Negeri Republik Indonesia Nomor 7 Tahun 2014 tentang Perubahan atas Peraturan Menteri Dalam Negeri Republik Indonesia Nomor 64 Tahun 2011 tentang Pedoman Penerbitan Rekomendasi Penelitian;
3. Peraturan Gubernur Sumatera Selatan Nomor 56 Tahun 2014 tentang Pedoman Penerbitan Rekomendasi Penelitian/Survei.
- b. Menimbang : Surat dari Dekan Fakultas Kesehatan Masyarakat Universitas Sriwijaya, Nomor : 0404/UN9.1.10/PL/2017, Tanggal : 27 Februari 2017, Hal : Mohon Izin Pengambilan Data Penelitian.

Memberikan rekomendasi penelitian/survey kepada :

- a. Nama/Obyek : NAJMAH, SKM, MPH.
- b. Jabatan/Tempat/Identitas : Pelajar/Mahasiswa/ Lrg. Jaya No. 151 RT. 007 RW. 002 Kel. 13 Ulu Kec. Seberang Ulu II Kota Palembang Provinsi Sumatera Selatan/ 1671036407830004.
- c. Lokasi Penelitian : 1. Dinas Kesehatan Provinsi Sumatera Selatan
2. Rumah Sakit Muhammad Hoesin Prov. Sumsel
- d. Lama Penelitian : 3 (tiga) Bulan.
- e. Anggota Tim Penelitian : -
- f. Bidang Penelitian : Kesehatan.
- g. Status Penelitian : Baru.
- h. Judul Proposal : Memampukan Ibu HIV Positif Usia Subur Untuk Mengakses Layanan Pencegahan Penularan HIV dari Ibu ke Anak (PPIA) di Indonesia.

Appendix C: Research methods and preparation

Appendix C.a: Preparation for fieldwork

C.a.1: Prior research applying Feminist Participatory Action research

Appendix table C. 1: Previous research applying Feminist Participatory Action Research

Aim of Study	Methods and Participants	Strengths**	Limitations
To create a space for children from divorced families to reconstruct their new lives (or rainbows) and be guided toward resilience and hope. Carr (2003)	Narrative study; Qualitative research paradigm of FPAR Discourse Analysis Reflection Process Four female adolescents with divorced parents	Individual and collective knowledge reconstruction of their new lives; developed narrative stories and creative visual methods using collage; participants' classmates attended their exhibition and gave feedback at school.	Limited co-researcher number (only four co-researchers); no clear explanation of researcher's positionality.
To explore the inter-relationships among women's health, experiences of violence, and access to housing. (Pranee Liamputtong & Ezzy, 2005; M Brinton Lykes & Hershberg, 2012; McIntyre, 2008; Reinharz & Davidman, 1992)	Photovoice methods Thematic analysis 42 female immigrants	Involved local advisory committee members; engaged local researchers, women-serving agencies, and non-profit housing organisations in research design and recruitment; explored intensive themes of data analysis with three different groups (local coordinator, advisory groups and local organisation leaders); generated broad policy recommendations.	No clear explanation of ways to link broad policy recommendations to policy makers.

Aim of Study	Methods and Participants	Strengths**	Limitations
<p>To describe the process of planning, developing and implementing a community-based project with Hmong women in a large Midwestern city, United States of America.</p> <p>(Botha & Hay, 2016)</p>	<p>Feminist PAR as methodology</p> <p>First Phase: providing 12 Hmong women with limited English, with participatory workshops on photovoice⁷⁷ methods</p> <p>Second Phase: providing eight Hmong women fluent in English, with monthly workshops to improve their organisational skills in building a non-profit organisation</p>	<p>Formed research advisory groups from practitioners of PAR and researchers who had experience working with Hmong people; provided clear steps in building trust and rapport; gave clear explanation of researcher's positionality (as an insider and outsider); involved workshops, skill building and empowering a process of creating process-orientation to develop a non-profit organisation for Hmong women; was aware of linguistic, educational and national differences.</p>	<p>Translation in the study could have resulted in misinterpretation.</p>
<p>To describe the development of a women's organisation in rural Guatemala that was created to respond to some of the psychological, economic and educational consequences of the war in Guatemala (Jategaonkar & Ponc, 2011)</p>	<p>Used photovoice methods</p> <p>19 Ixil women</p>	<p>Addressed outsider and insider positions clearly; involved local Ixil leaders throughout research and publication process; knowledge construction was performed through photography-based PAR using photovoice; was aware of linguistic differences, educational and national differences</p>	<p>Translation in the study could have resulted in misinterpretation</p>

⁷⁷ Photovoice is 'a process by which people can identify, represent, and enhance their community through a specific photographic technique' (Wang, 1997, page number needed)

C.a.3: Recruitment posters

**WAKTUNYA PEREMPUAN / IBU POSITIF HIV
BICARA DAN BERBAGI CERITA**

BUTUH PESERTA PENELITIAN

Tujuan dari penelitian ini adalah untuk memberikan ruang untuk Anda berbagi ide dan aspirasi terkait memampukan ibu positif usia subur untuk mengakses layanan Pencegahan Penularan HIV dari Ibu ke anak (PPIA). Setiap ibu positif dan ibu hamil positif mempunyai pengalaman, suara dan perspektif yang unik bagaimana mengatasi masalah ibu sendiri sesuai dengan kehidupan sosial, budaya dan agama ibu.

Kriteria Peserta Penelitian :

- 1) Ibu/Perempuan positif Usia Subur yang positif HIV (15-49 tahun)
- 2) Tinggal di Kota Palembang dan sekitarnya di Sumatera Selatan
- 3) Berkomitmen untuk berbagi ide dan aspirasi selama diskusi

Penelitian meliputi: **4-6 pertemuan** diskusi kelompok terarah (waktu dan tempat sesuai kesepakatan)

Jika kalian memenuhi persyaratan dan ingin berpartisipasi pada penelitian ini, hubungi **NAJMAH**
email : najem240783@gmail.com
sms/WA : 0813-6932-5568

**transportasi dan makanan/minuman akan disediakan untuk peserta yang terseleksi*

Disetujui oleh Komite Etik Universitas Teknologi Auckland pada 7 Maret 2017, dengan nomor referensi AUTEK 17/22
Disetujui oleh Komite Etik Universitas Sriwijaya 13 Maret 2017, dengan No. 39/keprsmhfkunsri/2017

**WAKTUNYA PEREMPUAN / IBU POSITIF HIV
BICARA DAN BERBAGI CERITA**

BUTUH PESERTA PENELITIAN

Tujuan dari penelitian ini adalah untuk memberikan ruang untuk Anda berbagi ide dan aspirasi terkait memampukan ibu positif usia subur untuk mengakses layanan Pencegahan Penularan HIV dari Ibu ke anak (PPIA). Setiap ibu positif dan ibu hamil positif mempunyai pengalaman, suara dan perspektif yang unik bagaimana mengatasi masalah ibu sendiri sesuai dengan kehidupan sosial, budaya dan agama ibu.

Kriteria Peserta Penelitian :

- 1) Ibu/Perempuan Usia Subur yang positif HIV (15-49 tahun)
- 2) Tinggal di Kota Palembang dan sekitarnya di Sumatera Selatan
- 3) Berkomitmen untuk berbagi ide dan aspirasi selama diskusi
- 4) Mengakses Layanan PPIA

Jika kalian memenuhi persyaratan dan ingin berpartisipasi pada penelitian ini, hubungi **NAJMAH**
email : najem240783@gmail.com
sms/WA : 0813-6932-5568

**transportasi dan makanan/minuman akan disediakan untuk peserta yang terseleksi*

Disetujui oleh Komite Etik Universitas Teknologi Auckland pada 7 Maret 2017, dengan nomor referensi AUTEK 17/22
Disetujui oleh Komite Etik Universitas Sriwijaya 13 Maret 2017, dengan No. 39/keprsmhfkunsri/2017

Appendix figure D.2: Advertisement for individual interviews and focus groups

Both advertisements discussed the need for participants for focus group discussions and interviews. Information in the flyers included the aim of study, inclusion criteria and my contact details.

Appendix D: Data

Appendix D.a: Poetry and songs

D.a.1: Modified lyrics of Cuk Ma Ilang (in English and Palembang dialect)

Cuk Ma Ilang is a traditional Palembangse folksong. The song contains four sentences in each verse, and the lyrics in the second verse respond to the first verse. Every two verses start with a similar chorus: “*Cuk Ma ilang; Mak ilang jaga batu; Dimano kucing belang* (Where your ginger cat is), *Disitu rumah aku* (That’s where my house is)”. This folksong is sung widely by all ages and can be understood as a sung poem about love, romance, friendships and old wisdom. The tones of this song can be emotional and melancholic, or cheerful and up-beat.

Cuk Ma Ilang Song with modified lyrics

Chorus

Cop/Cuk Ma ilang

Mak ilang jaga batu

Where your ginger cat is

That’s where my house is

(repeated chorus after verse 2)

Verse 1

Oi..my children, don’t you be afraid

HIV test is not scary

Hey mom, I am not afraid of HIV test, but

To ask for my partner is not as easy as you said.

Verse 2

Hi mothers, don’t be ignorant

Today’s men may do mischievous deeds

How come we know they do mischievous deeds

If both partners did not do HIV test

Verse 3

Come on, midwives offer me
An HIV test so my child will be healthy
Are you positive?
I don't want to take the risk

Verse 4

I want to get an HIV test
For my health and my child's
Or midwife, do you want to get infected?
If I were also positive

Chorus:

Cop/Cuk mak ilang
Mak ilang jaga batu
Dimano koceng belang
Disitu rumah aku

Verse 1

*Oi anak aku janganlah takut
Tes HIV idak menakutkan
Bukan mak itu oi mak aku
Ngologik dio dak semudah itu*

Verse 2

*O ibu-ibu janganlah lolo
Zaman sekarang lanang dak karuan
Oi makmanao aku na tahu
Aman idak tes duo-duonyo*

Verse 3

*Payo bu bidan tawari aku
Tes HIV biar anakku sehat
Apo ibu sakit HIV
Aku dak galak ambil resiko ibu*

Verse 4

*Aku galak nian dites HIV
Demi kesehatan aku samo budak
Apo bu bidan galak tertular
Kalo taunyo aku positif jugo*

Link to song performance: <https://www.youtube.com/watch?v=APKaNT7SYQ8>

D.a.2: Mona's poem (Indonesian and English versions)

*Untuk Putriku kesayanganku, Zee
Zee cepatlah tumbuh
Telusuri dunia ini
Yang penuh warna warni
Ceriamu disini
Cukup hapuskan sedihmu
Zee peri kecilku
Teruslah menari
Lentikkan tanganmu yang mungil
Ze wajahmu yang lucu
Hapuskan tangisku
Bernyanyilah lagu yang ceria
Petikkan gitarmu
Teriakkan keinginanmu
Sikap lembutmu akan merubah dunia
Menjadi Damai...
Melangkahlah terus gapai mimpimu*

To Zee, my dearest little angel

Zee, grow up faster
Explore the world
With full colours
Your happiness

Enough to wipe off my tears
Zee, my little angel
Your little beautiful finger
Dance to the music

Zee, your angelic face
Wipe off my tears
Sing a cheerful song
Play your guitar

Harness your ambition
Being gentle with your world
Be peaceful
Keep on living and embrace your ambition

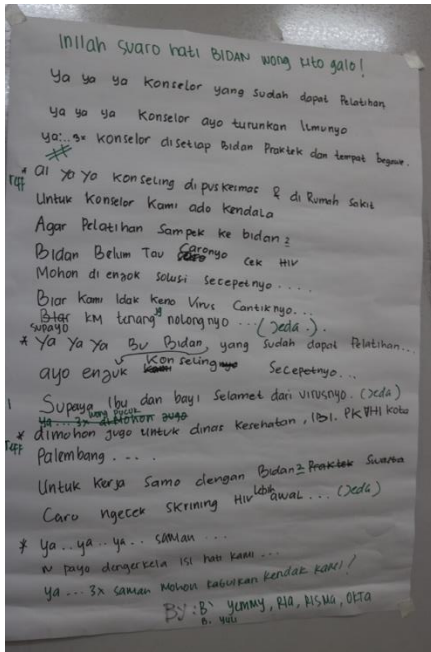
D.a.3: Transcript of Dr Zizi in Indonesia

Untuk petugas kesehatan, kasus HIV adalah kasus yang sangat ditakuti, tetapi sebenarnya tidak perlu ditakuti karena kalau kita takut,

Kita akan seperti seorang yang berkelahi: akan lebih enak kalau kita berkelahi berhadap-hadapan daripada kita dipukul dari belakang. Nah, seperti itu juga pasien HIV, pasien HIV itu kalau mereka tidak mengaku, itu seperti kita dipukul dari belakang. Kalau mereka mengaku, kita berhadapan dan kita lebih waspada untuk menanganinya. Sehingga, kalau pasien HIV ini dirangkul, mereka juga akan lebih terbuka dan kita juga lebih aman menangani pasien ini, lebih waspada daripada kalau mereka tidak mengaku. Sebagai pengidap HIV maka, lebih tidak aman bagi kita apalagi dengan pelayanan kesehatan yang tidak standar, kalau pasien kita layani dengan standar yang baku, kita pun akan lebih terlindungi. Daripada mereka tidak mengaku, maka yang lebih ditekankan bahwa penularan untuk anaknya akan lebih tinggi kalau mereka tidak mengaku, soalnya pelayanan untuk persalinan pada ibu hamil dengan ibu hamil dan yang lainnya itu lebih cenderung ada sedikit perlakuan khusus, sehingga penularannya akan lebih sedikit. Jadi untuk petugas kesehatan, marilah bersama-sama kita merangkul pasien HIV ini agar penularan kepada generasi selanjutnya, pada anak-anaknya akan lebih sedikit dan minimal sekali.

D.a.4: Modified lyrics of Ya Saman – Inilah Suara Bidan Wong Kito Galo

Link to this song performance: https://www.youtube.com/watch?v=DIGVTaZnT_o.



***Ya ya ya konselor yang sudah dapat pelatihan
Ya ya ya konselor ayo turunkan ilmunya
Ya ya ya konselor di setiap bidan praktek dan
tempat begawe*

*Ai ya ya konseling di puskesmas dan di rumah
sakit
Untuk konselor kami ada kendala
Agar pelatihan sampai ke bidan-bidan
Bidan belum tau caranya cek HIV
Mohon di ajak solusi secepatnya...
Biar kami idak keno virus cantiknya...
Biar km tenang nolongnyo... (Jeda)*

***Ya ya ya Bu bidan yang sudah dapat pelatihan
Ayoujuk konseling secepatnya
Supaya ibu dan bayi selamat dari virusnyo (jeda)*

Appendix figure D.3: Creative output: handwritten lyrics of song

*Di mohon jugo untuk dinas kesehatan, IBI, PKHVI Kota Palembang
Untuk kerjasama dengan bidan-bidan praktek swasta
Caro ngecek skrining HIV lebih awal (Jeda)*

***Ya...ya...ya....Saman, Payo dengerkenlah isi hati kami
Ya ya ya saman, mohon kabulkan kendak kami*

D.a.5: Modified poem with theme of communication, information, and education

Pantun pertama

Ibu Ani beli tomat

Tomat dibeli untuk soto babat

Bagaimana kami mau sehat

*Kalau informasi HIV pun tidak kami
dapat*

Bangun rumah bersekat-sekat

Pantun kedua

Pas istirahat minum jus alpukat

*Ayo gerakkan Pusat informasi kesehatan
masyarakat*

First verse

Mrs. Ani buys some tomatoes

Tomatoes for making the soup....

How can we healthier

*If we don't even obtain information about
HIV*

Second verse

Build a house with lots of walls

*Having some avocado smoothies during
our break*

*Supaya ibu anak selamat dari HIV dan
hidup sehat*

C'mon empower our information centre
for community health

So mothers and babies are healthy and
HIV free

D.a.6: Modified poem with theme of communication, information, and education

By a group of NGO workers

Lirik 1

*Saya si ibu hamil 5 bulan datang ke rumah sakit untuk checkup kandungan
Diperiksa darah HIV positif*

Lirik 2

*Saya bingung saya sedih saya takut
Apa yang harus aku lakukan?
Datanglah pendamping mensupport saya
Mengenalkan program PPIA
Program PPIA memakai rujukan*

*Rujukan PPIA membuat saya lelah
Dari Rumah sakit sampai layanan terus sampai proses kelahiran
Normal atau sesar sampai ke pengobatan anak
Anak saya sehat dan anak saya pun selamat*

Note: Link to their performance: <https://www.youtube.com/watch?v=9ZxSyzt2e9M>

Appendix D.b: Role play script

The scenes and storylines and full script of the role play by Sehati A (a group of six HIV-positive women)

The story was inspired by the experiences of the two group members who had accessed PMTCT services in the early stages of their pregnancies in *puskesmas* and delivered their babies in hospital. Their babies received prophylaxis treatment for the first 18 months of their lives and finally were confirmed HIV free. They expressed to me that they were the happiest mothers, because they could raise their children with love.

The first scene of the role play depicts the journey of an HIV-positive pregnant woman named Intan, having a consultation with her midwife. Intan, with some hesitation, discloses her HIV status to her midwife. Having the knowledge related to HIV and PMTCT services, the midwife is equipped professionally to assess Intan's pregnancy in her clinic without any prejudice. The midwife prescribes some nausea tablets and vitamins for her. The midwife writes a referral letter for Intan to visit the closest Voluntary Counselling Testing Centre (VCT) to access comprehensive PMTCT services in a referral hospital.



Appendix figure D.4: Puppet show showing Intan accessing PMTCT services

English translations: *Ibu, Bu* (Mrs), *dokter* (doctor), *suami* (husband), *ibu hamil (+) HIV* (a pregnant woman with HIV), *bidan* (midwife), and *pihak rumah sakit* (hospital administrative staff).

The following dialogue is of Intan and the midwife during her ANC visit

Midwife	Yes, <i>Ibu</i> , come in.
Intan	<i>Ibu</i> , I want to check my pregnancy.
Midwife	How many months now?
Intan	Just two months.
Midwife	Have you been here before?
Intan	No, this is my first time.
Midwife	Yes, please lay down first.
Intan	<i>Bu</i>I am (a bit hesitant) I got an HIV... am infected with HIV.
Midwife	Ooo...No worries, do you have any complaint?
Intan	Vomiting and nausea.
Midwife	I will give you some vitamins and something to help with the nausea.
Intan	Yes, <i>bu</i> ...
Midwife	I will prepare a referral letter to VCT in a hospital.
Intan	Yes, <i>bu</i> .

Link to scenes 1-5 of the puppet show:
<https://www.youtube.com/watch?v=xn0bfC2f25g>

In the second scene, Intan and her husband visit the hospital straight away. A nurse welcomes Intan and her husband, receives the referral letter and calls a doctor to meet them. The doctor explains the process and the procedures to the couple. Intan then is referred to an obstetrician within the PMTCT team and told to come back at six or seven months pregnant to plan for her Caesarean section. Intan is advised to continue her regular antenatal care with her current midwife.

The third scene includes an emergency unit in a hospital. Intan and her husband arrive at the hospital in a rush as Intan starts to feel contractions ahead of her planned Caesarean. The admission nurse asks her some initial questions, but the nurse's attitude dramatically changes once Intan mentions her HIV status. To her surprise, Intan overhears the nurses gossiping about her HIV status and spelling out *ODHA (Orang Dengan HIV/AIDS)* or PLWH (People Living with HIV) to her colleagues, and they tell her to be cautious with Intan, for example, to use multiple gloves when examining her. Fortunately, the PMTCT team arrives quickly to see her, and the team quickly prepares for the emergency Caesarean Section. The obstetrician on the PMTCT team, says "come on be quick, prepare the operation room, the operation is now". The team is aware that the risk of HIV transmission to the baby can be minimised by undertaking the Caesarean operation as soon as possible.

Scene four outlined below relates to post-delivery, when Intan and her baby are transferred to the maternity ward. Intan feels relieved that her baby is delivered safely by Caesarean section. However, she is still very upset by the discriminatory treatment and bullying she received from the admission nurses prior to the arrival of the PMTCT team. Fortunately, she chooses to exercise her right to fair treatment for HIV-positive clients and calls a doctor in the Voluntary and Counselling Testing (VCT) centre to complain about the discrimination.

The following dialogue is from Scene four when Intan is in the maternity ward post-delivery.

	The patient phones a doctor in the VCT centre (sounds of a phone ringing)
Intan	Hello
Doctor	Yes
Intan	Hello Doctor, oh my God (<i>Ya Allah</i>), please help me, doctor, I was asked to provide my own plastic cover for my baby's bed sheet and I cannot use the hospital one. I felt very upset, please help me, doctor. I felt discriminated (<i>terkucil</i>), I was cornered (<i>cak tersudut</i>) in this

hospital. Oh, my God, I feel so disappointed to come to this hospital, please help me doctor.

Doctor Be patient. I will come and see you as soon as I can. I am currently still with another patient, but I will be there soon.

Intan Yes, doctor, please help me.

Then a doctor comes to see Intan in her room in maternity ward room

(Background music playing.)

In Scene five, once the doctor arrives and hears Intan's complaints, he calls the duty nurse responsible for Intan. The doctor listens to the explanation from the nurse and educates her with correct information about HIV transmission. The doctor then instructs the nurse to search on the Internet with her mobile phone for current information about HIV and about the professional conduct of staff working with HIV patients, and to learn about the rights of HIV patients to receive equitable, and quality, non-discriminatory treatment. In the next few days, Intan notices markedly different treatment from the nurses, as they are kinder and friendlier. Intan also receives very clear information about appropriate contraceptive methods for HIV-positive couples to prevent unintended pregnancies and provide prophylaxis treatment for her baby. The story ends with Intan, her husband, and baby going home.

A few minutes later...

Doctor There was a complaint from an HIV-positive patient, why were they discriminated (against)?

Midwife I asked the patient to buy a plastic cover (for her bed), doctor, we are afraid of contracting her blood

Doctor Are all of you afraid of getting HIV, aren't you! There is a low risk if the blood has been outside their body, the virus will die in a few

minutes. There is no risk of HIV transmission through saliva, hugging each other, patient's clothes, except if you had a wound and there was their blood, there was a possibility to have a risk

Midwife We were so sorry, doctor

Doctor Please, treat HIV patients similar to other patients, please do not discriminate (against) them. All of you should take another course about HIV.

In the future, I hope there would be no complaint again about this matter with other HIV patients. Please provide supportive environment for our patients.

All of you have an expensive mobile phone, please, open Google then seek information on the online platform about HIV and its transmission

Midwife Yes, doctor

Appendix D.c: Putri's and Oda's stories

D.c.1: Putri's Story

Putri and her husband, Joko, graduated from high school and were quite poor. The family lived in a rented tiny one-bedroom house. Putri run a small bric-a-brac stall next to the house (*warung sembako*). In her stall, she sold rice, sugars, cheap snacks, and flour. Both Putri and Joko were HIV positive. Joko was a former injecting drug user (IDU) and they only found out about Joko's late HIV status in 2007. The finding of Joko's HIV status happened accidentally following his motorcycle accident. At that time Joko was diagnosed with an opportunistic infection of HIV and brain infections, the latter of which affected his vision. Their two children of 14 and 6 years old were HIV negative.

Putri's recalled story was based on her own decision to make a choice to have a second child free of HIV after being confirmed HIV positive. She reflected on her own

experience after browsing information on the internet, and then arranged for both of them to meet with the specialists at a local VCT clinic. In 2011, after both of their CD4 counts reached over 300 cells/mm³ (indicating that their immunity was at good level), they stopped using condoms for two weeks and Putri became pregnant. Joko saved money to have Putri's status checked by a private specialist obstetrician, which cost him about NZ\$30-\$40 (Rp 300,000-Rp 400,000) per monthly visit. The baby was delivered by Caesarean section in a public hospital and then they had to wait for 18 months to get confirmation of the baby's HIV status. To their relief, the baby was confirmed HIV negative in 2013. Upon receiving that news, the family had a thanksgiving celebration or *syukuran* by cooking some goats and special dishes to share with their neighbours.

D.c.2: Oda's Story

I met both Oda and Hasan, during the hospitalisation of their youngest child, Malin, aged 18 months. Malin was severely malnourished due to HIV and his weight was only 4.6 kg. Oda found out about her HIV status only after Malin was diagnosed HIV at the age of 18 months. After a series of debilitating illness and infection, including Malaria, fungal infections in his mouth, and intestinal infections, Oda and Hasan decided to take Malin to Palembang. It took them eight hours by car to travel from their place to Palembang. Malin was first treated for malnourishment for about three weeks before being offered an HIV test. The test results were positive, and straight away, Malin was quickly transferred to an isolated room. Later, Oda was also confirmed HIV positive, but Hasan's test was negative. Oda and Hasan suspected that Oda was the victim of unsterilised medical equipment during her third delivery in a limited service rural clinic in Lahat.

Appendix E: Key terms

Appendix E.a: Key terms

AIDS: Acquired Immunodeficiency Syndrome is late stage HIV infection in which people living with AIDS are particularly vulnerable to suffer from number of severe illnesses, called opportunistic infections, such as tuberculosis and other infections of the brain, liver, cancer, and diseases (HIV i-BASE, 2016; Najmah, 2016; Siedner & Triant, 2018).

ARV: Anti-retroviral or ARV medicine, is one biomedical therapy can help to increase the immune systems of people living with HIV by controlling the growth of the HIV in the blood cells. With long-life availability and adherence of ART [Antiretroviral Therapy (ART) (a combination of at least three different drugs)], HIV is as a chronic disease.

Concentrated HIV epidemic: “HIV has spread rapidly in one or more populations but is not well established in the general population. Typically, the prevalence is over five percent in sub-populations while remaining under one percent in the general population, although these thresholds must be interpreted with caution. In a concentrated HIV epidemic there is still the opportunity to focus HIV prevention, treatment, care, and support efforts on the most affected sub-populations, while recognising that no sub-population is fully self-contained” (UNAIDS, 2011, p 8).

Generalised epidemic: An HIV epidemic that is self-sustaining through heterosexual transmission. In a generalised epidemic, HIV prevalence usually exceeds one percent among pregnant women attending antenatal clinics (UNAIDS, 2011, p 12).

HIV: Human Immunodeficiency Virus attacks a type of white blood cell in the immune system called a T-helper or CD4 cell.

Key population⁷⁸ at higher risk of HIV exposure: Key populations are “distinct from vulnerable populations, which are subject to societal pressures or social circumstances that may make them more vulnerable to exposure to infections, including HIV”

(UNAIDS, 2011, p 8). Key populations at higher risk of HIV exposure refers to “those most likely to be exposed to HIV or to transmit it – their engagement is critical to a successful HIV response. In most settings, men who have sex with men, transgender persons, people who inject drugs, sex workers and their clients, and seronegative partners in sero-discordant couples are at higher risk of HIV exposure to HIV than other people. There is a strong link between various kinds of mobility and heightened risk of HIV exposure, depending on the reason for mobility and the extent to which people are outside their social context and norms” (UNAIDS, 2015, p. 18).

PMTCT services: Prevention of Mother-to-Child of HIV Transmission services offers a wide range of services for women and infants. Preventing of mother-to-child of HIV transmission offers interrelated medical test and biomedical therapy on antenatal HIV testing, ARV therapy for HIV-positive pregnant women and prophylaxis therapy for babies born from HIV-positive mothers, safe practice of labour, and HIV test for their infants. A range of services of PMTCT services also offers a holistic program, known as the four-pronged strategy of PMTCT services, to prevent HIV among women of childbearing age by providing antenatal HIV testing (prong 1); to prevent unintended pregnancy among HIV-positive women and their spouse (prong 2) and to prevent MTCT of HIV among pregnant women living with HIV respectively (prong 3); and to focus on on-going social and psychological support and availability of ARV therapy for children living with HIV and their mothers and partners living with HIV (prong 4) (WHO, 2018).

Mother-to-child HIV transmission - vertical transmission: HIV can be transmitted from a woman living with HIV to her unborn baby during pregnancy, childbirth, and breastfeeding or vertical transmission. Without intervention, 20-50 % babies born from HIV-positive mothers are at risk to contracting HIV (De Cock et al., 2000; MoH, 2013e; Tudor Car et al., 2011)

Spider’s web: “Epidemiologists recognize that there are many reasons for disease epidemics, as encapsulated by the metaphor of the webs of spider’s web, with the factors that encourage the spread of HIV and compound the impacts of AIDS extending outwards. Nearest to the centre of the web are the bio-medical factors which influence the efficacy of HIV transmission, such as different types of HIV, and the susceptibility of the individual according to his or her state of health, including the presence of sexually transmitted infections, beyond those medical factors lie the behavioral ones,

such as the number of sexual partners, the age gap between them, and use of condoms. The webs then stretch further out to the micro-environment in which people live, including social, cultural, and economic influences which affect their decision making and sexual behavior, such as gender relations, poverty, and migration. The outside edges of the web concern the macro-environment of regional, and finally global, factors, including national wealth, income distribution, and the effects of conflict” (Holden, 2003, p. 65).