My Baby Deserves Love, not HIV

Enabling HIV-positive Indonesian women to access prevention of mother-to-child transmission of HIV services

Najmah

A thesis submitted to Auckland University of Technology in
fulfilment of the requirements
for the degree of Doctor of Philosophy

Supervised by Dr Sari Andajani and Associate Professor Sharyn Graham Davies

Public Health and Psychosocial Studies

Faculty of Health and Environmental Science

2019

ABSTRACT

Getting married and having children is part of the social, cultural, and religious norms of Indonesian people, including those of women living with Human Immunodeficiency Virus (HIV). Pregnancies occur amongst these women. Unfortunately, only 10% of all pregnant women living with HIV, access Prevention of Mother-to-Child Transmission of HIV, or PMTCT services, annually. Without intervention, half of all babies born to mothers with HIV are at risk of contracting HIV through the mother's pregnancy, delivery or from breastfeeding and three in four children's deaths from Acquired Immunodeficiency Syndrome (AIDS) occurred before the age of five years.

My research considers how to enable HIV-positive women to access PMTCT services, specifically focussing on heterosexually married mothers. I believe HIV-positive women are the real experts in terms of what they need to enhance their access to PMTCT services. My research allowed me to work with 18 HIV-positive women, 26 health workers, nine Non-Governmental Organisation (NGO) workers, and over 12 HIV policymakers through a series of focus group discussions, informal interviews, and visual methods.

Three original theoretical contributions in this dissertation are the concept of marital deception, the concept of intersectionality and women's vulnerability to HIV and the concept of HIV-related stigma or shame in the Indonesian context. My research shows that every Indonesian woman is at risk of HIV. HIV transmission is a complex issue, especially for mothers and wives within a patriarchal Islamic society. It is usually the man who contracts HIV through high-risk behaviours and passes it on to his wife, often with his knowledge, although sometimes unknowingly. After being confirmed as HIV positive, women may feel ostracised and resist accessing HIV care for fear of discrimination. The shame related to HIV means people may not talk about HIV within a family, community or even in health settings. Sadly, without HIV testing and intervention, a pregnant woman with HIV, therefore, her risk being unaware of her own HIV status and may risk HIV transmission to her child. This research reveals intersected barriers to accessing PMTCT services and indicates the need for holistic solutions to enhance accessibility to these services to reduce HIV risk to an estimated 30 babies at risk of HIV every day in Indonesia.

This thesis has provided deeper insights into Feminist-Participatory Action Research (FPAR) as an important methodology to create a safe collective space for marginalised women and reveal factors that enable HIV-positive women to access PMTCT, such as the acknowledgment of wives and mothers at risk of HIV and the need to accommodate the socio-cultural and moral contexts of women's lives within PMTCT programmes. This study will be the beginning of ongoing research into women's participation in HIV programmes and HIV policy development and inspire further research. By producing audio-visual materials, the women's aspirations can travel visually and verbally and act as influence on the provision of appropriate access to PMTCT services.

Keywords: HIV, PMTCT, aspiration, trust, participation, feminist-participatory action research, Indonesian women

Table of Contents

ABSTRACT ii

Table of Contents iv

Glossary of Indonesian, Palembang, and Arabic words xiv

Abbreviations xviii

List of Figures xx

List of Appendix xxiii

List of Tables xxiv

List of Text-boxes xxvi

Opening words xxviii

Acknowledgements xxix

Ethics Approval xxxiii

Chapter 1. Introduction 1

1. *Prologue* *1*
2. *Background to the study* *3*
    - HIV among ibu rumah tangga 4
    - HIV among children 6
    - Prevention of mother-to-child of HIV transmission (PMTCT): Chances and challenges 7
3. *Research gap* *9*
4. *Aim of this study* *11*
5. *Why I came to focus on HIV* *11*
6. *Overview of key groups for HIV programmes in Indonesia* *13*
7. *The Field Site: Palembang, the capital city of South Sumatra* *15*
    - Indonesia: An overview 15
    - Indonesia: Snapshots of Indonesian women's status and expectations 17
    - Palembang (research area): Socio-demographic profile 20
    - Palembang: Health sector 21
    - Palembang: HIV prevalence and programmes 22
8. *My position as a researcher* *24*

Being an insider 25
Being an outsider 26
9. *Significance of the study* *27*
10. *Structure of the thesis* *28*
Introduction (Chapter 1) 28
The context of women: Indonesian women's vulnerability to HIV (Chapter 2) 29
Prevention of mother-to-child transmission of HIV: A global and Indonesia context (Chapter 3) 29
Methodology (Chapter 4) 29
Findings (Chapters 5, 6, 7) 29
Discussion (Chapter 8) 30
Translating Research Knowledge into Practice (Chapter 9) 31
Chapter 2. The context of women: Indonesian women's vulnerability to HIV **32**
1. *Introduction* *32*
2. *Vulnerability to HIV* *33*
The social cultural factors of women 33
Female reproductive systems 35
3. *Expectations of women in Indonesia* *36*
Indonesian women and government policies 37
Defining gender ideology in patriarchal society: Historical background 37
Promoting monogamous registered marriages 40
Restricting polygamous marriages and divorces 41
Regulating the roles of wives and husbands but providing opportunities for women in the public sphere 42
Indonesian women and Islamic values 44
Defining heterosexual gender morality: historical context 44
Promoting monogamous marriage and restricting polygamy and divorce47
Being a good wife and mother 49
4. *Societal Reality of women in Indonesia: Why women are vulnerable to HIV in Indonesia* *51*
HIV knowledge among Indonesian women 51
Sexual double standards 53

Lack of use of condoms and non-consented sex among married couples 53
Fears of disclosure of sexual orientation and HIV status within heterosexual hegemony 54
Social inequality and stigmatisation of HIV-positive women 55
Institutionalised gendered discrimination in health settings 55
Institutionalised gendered discrimination in governmental policies 56
5. *Summary* *57*

Chapter 3. Prevention of mother to child transmission of HIV: A global and Indonesian context **60**

1. *Introduction* *60*
2. *PMTCT at a global level* *61*
    - A global history of PMTCT: 1994-2013 61
        - When PMTCT came about - global context 62
        - What happened between 2000 and 2013? 63
    - Global PMTCT programmes in 2013-2017 65
        - World Health Organisation: Four-prongs of PMTCT services 65
        - UNAIDS: Start Free, Stay Free, AIDs Free 66
        - Key players of PMTCT programmes 66
        - What worked and what did not work 68
    - Barriers to access PMTCT services at global level 70
        - Health systems barriers 70
        - Economic barriers 71
        - Information barriers 72
        - Cultural barriers 73
3. *PMTCT in Indonesia* *74*
    - History of PMTCT in Indonesia 75
    - Programmes on offer between 2013-2017 76
        - Prong 1: Prevention of HIV among women of reproductive age 77
        - Prong 2: Preventing unintended pregnancies among HIV-positive women 78
        - Prong 3: Preventing HIV transmission from a HIV-positive woman to her unborn baby 80

Prong 4: Providing appropriate treatment, care, and support to mothers living with HIV, and their children and families 80

Ministry of Health Regulations 2013-2017 81

Key players of PMTCT 83

HIV-focused non-governmental organisations 86

International Donors 87

Barriers to accessing PMTCT services in Indonesia 89

Health systems barriers 89

Economic barriers 92

Information barriers 93

Barriers caused by gender discrimination 94

4. *Summary of PMTCT in global and Indonesian contexts* *95*

Chapter 4. Methodology **97**

1. *Research paradigm* *97*

Feminist epistemology 98

Empowerment in feminist research 100

Feminist Participatory Action Research (FPAR) 102

Data collection methods 106

2. *Pre-Fieldwork* *108*

Pre-fieldwork FGD practice 108

Pre-fieldwork interview practice 110

Lessons to be learned during pre-fieldwork practice 111

3. *Field-study design* *112*

Formulation of the RAG 112

Recruitment of research facilitators 113

Recruitment of participants 115

Recruitment of HIV-positive women 115

Recruitment of health workers and NGO workers 121

Recruitment of HIV policy makers, and health and women's organisations 122

4. *Creating space with HIV-positive women in research and other groups* *123*

Overview of data generation cycle 123

Collective creative works 125

Individual creative works 128

Other groups: Linking the voices and aspirations 128

5. *Data analysis* *129*

6. *Research ethics* *131*

Obtaining ethics approval and in-country research permission 131

Protection of participants 132

Ethical challenges 133

7. *Summary* *134*

Chapter 5. The life context of HIV-positive Indonesian women 137

1. *Mawar: Experiences of divorce, substance drugs, and promiscuity* *138*

Mawar's timeline 138

Life after divorce 138

Non-disclosure of her HIV status prior to her second marriage 140

Reflecting on Mawar's vulnerability to contract or spread HIV 141

Tension of being a divorcee 141

Deception within marriage 142

Poor knowledge related to HIV 143

2. *Oneng's story: A low-income HIV-positive widow raising an HIV-positive daughter* *143*

Oneng's timeline 144

Finding out about her HIV status 144

Oneng's married life 145

Suleman's sickness 145

Reflecting on Oneng's and her daughter's HIV vulnerability 146

Being a wife and mother within societal expectation of an Indonesian woman 146

Being naïve and powerless 147

3. *Mira's story: Seeking PMTCT services with her husband* *148*

Key timeline of Mira 149

Preventing mother-to-child transmission 149

Vulnerability and discriminatory practice 150

Syphilis and HIV vulnerability 150

Men having sex with men (MSM) and pressure to marriage 151

Reflecting on Mira's story 152

4. *HIV and pregnancy: A complex story of transmission* *153*

The complexity of HIV transmission: Individual experience 154

The complexity of HIV transmission: Collective knowledge 155

Indonesian vulnerability to HIV: Complex intersections 157

5. *Summary* *161*

Chapter 6. Barriers to accessing PMTCT services **162**

1. *Introduction* *162*

2. *Getting tested or not* *163*

Breaches of confidentiality 164

The culture of kepo 164

Health workers' intention to protect their peers 165

Lack of professionalism 165

HIV screening is only being implemented for one year 166

Lack of coordination and distrust between host organisations 167

Inadequate and limited HIV training for midwives 168

Relying on the subjective judgement of health workers 169

3. *HIV positive: Experiences after the diagnosis* *170*

How the health system failed Ani 172

Health workers' fears of working with HIV positive women 173

"It is normal" to be fearful of HIV infection 174

Avoidance along a continuum 175

The referral system: Endless red tape 175

4. *Gendered morality: Discrimination and women's access to PMTCT services* *177*

Stories of Anti and Lela: Needing a husband permission to HIV testing 179

HIV testing and the difficulty of implementation 179

Unequal rights affecting women's decisions around their own reproductive and sexual health 180

Silenced voices of health professionals powerless to exercise their professional role 181

Adel's story: A woman is responsible for spreading HIV 182

Lilis' story: A woman's space with a trained midwife in antenatal care services in puskesmas 184
5. *Summary* *185*

Chapter 7. What women need to enhance their access to PMTCT services 188

1. *Introduction* *189*
2. *Individual sphere: What women need to access PMTCT services* *189*
Being resourceful 190
Being knowledgeable 192
3. *Family sphere: What husbands should do to enable women to access PMTCT services* *194*
Disclosing HIV status 194
Supportive marriage environment: Acceptance of HIV status 196
4. *What health workers need to do to enable women to access PMTCT services* *198*
A reflection of a lived experience of an HIV-positive woman with a child 198
Strategies to solve institutionalised discrimination in health settings 199
    Peer education for interpersonal skills 200
    Online peer education 200
    Peer education in partnership with health organisations 203
    Confidential phone line for constructive feedback 204
5. *What government needs to do to enable women to access PMTCT services* *206*
Simple language: "Let's protect mothers, children, and health workers from HIV" 206
Midwives play a key role 210
Woman's space for confidentiality and privacy 211
Shorter referral procedures 211
6. *Summary: Intersecting strategies to enhance access to PMTCT services* *212*

Chapter 8. Discussion 214

1. *The conceptualisation of 'marital deception' and HIV vulnerability in women* *215*
Marital deception and unclear regulation in health settings 216
Marital deception within a marital continuum 217
Marital deception in a non-heterosexual relationship 217

Marital deception and non-consentual sex 218

2. *Intersectionality and Women's Vulnerability to HIV* *219*

Women's economic dependency on husband 220

Education's level of women and HIV literacy 221

Women's marital status and HIV's disclosure 222

The notion of motherhood 223

3. *HIV Related Stigma in Indonesian Context* *225*

Understanding stigma from HIV-positive women and health workers 225

Intersectional stigma and HIV vulnerability 229

4. *Reflection* *231*

Chapter 9. Translating Research Knowledge into Practice **235**

1. *PMTCT policies and practices based on four prongs* *236*

Prong 1: Plan of action for prevention of HIV among women of reproductive age 239

Prong 1 - Recommendation 1: Using a simple, local-relevant and non-judgmental language 239

Prong 1 - recommendation 2: Using social media 240

Prong 1 - recommendation 3: Endorsing a transformative change in communicating the PMTCT programme to the grassroots. 240

Prong 2: Plan of action for prevention of unintended pregnancies among HIV-positive women 242

Prong 3: Plan of action for preventing HIV transmission from a HIV-positive woman to her unborn baby 243

Prong 3 – recommendation 1: Giving midwives a central role in HIV screening 243

Prong 3 – recommendation 2: Rights-based training for health professional on universal health access 245

Prong 4: Plan for action – providing appropriate treatment, care, and support to mother living with HIV, and their children and families 247

2. *Methodological Implications: FPAR as an important methodology to create a safe collective space for HIV positive women* *248*

First Principle: Cultivating trust with women 249

Second Principle: Creating a space for non-discriminatory and open dialogue with a critical analysis of gender relations 249
Third Principle: Centring women within a safe physical environment 251
Fourth Principal: Honouring the voice women through partnership and varieties of representations in expressing aspirations 252
Fifth Principle: Advocating partnership for responsive transformative change 252
Sixth principle: Proposing an intersectionality lens: accommodating the multi-layered and complex interactions of the socio-cultural and political context of women's lives 253
3. *Limitations of the study* *254*
Participants 254
Study site 255
Time limitation 255
Information bias 255
4. *Closing statement* *256*
Reference list **258**
Appendices 286
Appendix A: Ethics approvals 286
Appendix A.a: Ethics approval from Auckland University of Technology 286
Appendix A.b: Ethics approval form University of Sriwijaya, Indonesia 288
Appendix B: Tools 289
Appendix B.a: Participant Information Sheets 289
Appendix B.b: Consent forms 319
Appendix B.c: Indicative interview and focus group discussion questions 329
Appendix B.c: Letters of support 332
Appendix C: Research methods and preparation 333
Appendix C.a: Preparation for fieldwork 333
Appendix D: Data 338
Appendix D.a: Poetry and songs 338

Appendix D.b: Role play script 347
Appendix D.c: Putri’s and Oda’s stories 351
Appendix E: Key terms 353
Appendix E.a: Key terms 353

Glossary of Indonesian, Palembang, and Arabic words

Alat medis tidak steril	Unsterile medical equipment
Alhamdulillah	Thanks to God
Anggaran Pendapatan dan Belanja Negara	State expenditure and budget
Angkatan kerja	Employed person
Badan Kesatuan Bangsa dan Politik	The National Unity and Politics
Badan Penyelenggaara Jaminan Sosial	BPJS (Social Insurance Administration)
Bekerja di kapal/pelaut	Sailor
Bergetar	Shaken
Bhineka Tunggal Ika	Unity in Diversity
Bidan	Midwives
Bina Gizi dan KIA	Section of Nutrition and Maternal and Child Health
Bina Kesehatan Ibu Hamil	Section of Pregnant Women Health
Bu	Mrs, Madam
Budak kos	In boarding house away from parents
Bumi Sriwijaya	Sriwijaya land
Buruh bangunan	Seasonal construction worker
Cabe cabean	Female students working as sex worker
Cewek matre	Woman seeking wealthy husband
Dewan Perwakilan Rakyat	House of Representative
Dharma Wanita	The five duties of women
Dinas Kesehatan	Public Health Office
Diperlakukan tidak adil	Treated with unfairness
Dokter	Doctor
Dosa	Sins
Idul Fitri (Eid Fitr)	Islamic religious holiday
Etnik Melayu	Malay ethnic group
Garis-Garis Besar Haluan Negara	Broad Guidelines of State Policy
Ibadah	Worship of Allah (God)
Ibu hamil positif HIV	HIV-positive pregnant women
Ibu rumah tangga	Wives, mothers and married women
Ibuism	(Social construction of) woman-hood

Ikatan Perempuan Positif Indonesia	HIV-positive women's association
Mu'amalah	Transaction between human beings
Intensifikasi khusus	Special intensification or HIV
Jaga muka	Lose face /save face
Janda hidup	Divorcee
Janda mati	Widows
Jijik	Disgusted
Kabupaten	Regency
Kalang kabut	Panicked
Kampung	Village
Kartu tanda penduduk	Identity card
Kartu keluarga	Family card
Kecamatan	District
Keluarga	Family
Keluarga sakinah, mawaddah and warohmah	Family with transquility, affection, and mercy
Kelurahan	Sub-district
Kepala bidang	Programme leader or manager
Kepo	Nosy, curious
Kesejahteraan Rakyat	Prosperous society
Keturunan	Offsprings/Bear children
Kodrat	Appropriate roles
Komisi Penanggulangan AIDS Nasional	National AIDs Commission
Kompilasi Hukum Islam	(Compilation of) Islam state law
Korban penyalahgunaan narkotika	Victims of drug abuse
Kota	City
Lelaki Suka Lelaki	Men who have sex with men
Mawaddah (Arabic)	Affection
Menakuti nakuti	Scare tactic
Menghindar secara terus menerus	Avoidance along a continuum
Menteri ekonomi dan kesejahteraan rakyat	Ministry of Economic and People Prosperity
Nakal	Badly behaved
Nama baik	Reputation

Nikah diam-diam	Secret marriages
Nikah siri	Unregistered marriages
Pacar	Boyfriends or girlfriends
Pecandu	Drug user
Pegawai negri sipil	Public servants or state workers
Pekerja seks	Female sex workers
Pelakor	Woman who steals another's husband
Pemberdayaan perempuan	Women's empowerment
Pemerintah daerah	Local Government
Pemerintah pusat	Central Government
Pengawas minum obat	Drug watchers
Penyakit pada populasi kunci	'Hooker disease'
Penyakit yang dicari dewek/sendiri	HIV is a disease due to one's behaviour
Perampas laki orang	Woman who steals another's husband
Peranan perempuan	Women's roles
Peraturan Kementerian Kesehatan	MoH regulation
Peraturan Presiden	Presidential decree
Perempuan baik-baik	Responsible, good women
Perempuan nakal	Promiscuous women
Positif atau idak	False positive
Posyandu	Maternal and children's centre
Puskesmas	Primary or community health services
Puskesmas pembantu	Public or community health sub-centre
Rahmah (Arabic)/ Rohman (Indonesian)	Mercy
Rasa malu	Social shaming
Ruang rawat inap	In-patient rooms
Sakoon (Arabic)/Sakinah (Indonesian)	Tranquility
Sanjo	Social visit after Ramadhan
Sehati	In solidarity we are together
Selingkuhan	Partners of extramarital relationship
Shabu	Methamphetamine
Sholeha	Pious
Sistem Informasi HIV-AIDS	Information system about HIV-AIDS
Soleha	Good or religious woman

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	Compuslory nine-year education
Wajib belajar duabelas tahun	Compuslory 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

Abbreviations

ADHA	*Anak dengan HIV-AIDS*
AFASS	Acceptable, Feasible, Affordable, Sustainable, and Safe
AIDS	Acquired Immunodeficiency Syndrome
APBN	*Anggaran Pendapatan dan Belanja Negara*
ARV	Anti-Retroviral Treatment
AUSAID	Australia Agency for International Development
AUTEC	Auckland University of Technology Ethics Committee
BPJS	*Badan Penyelengara Jaminian Sosial* (Social Insurance Administration Organisation)
CCM	Country Coordinating Mechanism
CST	Counselling Support and Testing
FPAR	Feminist-Participatory Action Research
GARPR	Global Aids Response Progress Reporting
GBHN	*Garis-Garis Besar Haluan Negara*
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GoI	Government of Indonesia
HIV	Human Immunodeficiency Virus
HSS	HIV sentinel surveillance
IATT	Inter-Agency Task Team
IBBS	Integrated Biological and Behavioural Survey
IPPI	Ikatan Perempuan Positif Indonesia
IUD	Intra Uterine Device
KHI	*Kompilasi Hukum Islam*
KIA	*Kesehatan Ibu dan Anak*
KK	*Kartu keluarga*
KPAN	*Komisi Penanggulangan AIDS Nasional*
KTP	*Kartu Tanda Penduduk*
LSL	*Lelaki Suka Lelaki* (i.e.MSM)
MCH	Maternal and Child Health
MDGs	Millenium Development Goals
Menkokesra	*Menteri ekonomi dan kesejahteraan rakyat*
MOH	Indonesian Ministry of Health

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

List of Figures

Figure 1.1: HIV prevalence among adults (15-49 years) and key populations in South-East Asia 4

Figure 1.2: Percentage of HIV-positive pregnant women in 2016 receiving effective ARV for PMTCT in countries with at least 10,000 HIV-positive pregnant women 9

Figure 1.3: HIV Vulnerability among married women in Indonesia. 14

Figure 1.4: Map of Indonesia 16

Figure 1.5: Map of Palembang, South Sumatra 20

Figure 1.6: Cumulative number of HIV in 20 cities/regencies South Sumatra (1995-April 2017) 23

Figure 2.1: Possible routes for transmission of HIV to women in the wider population in Thailand (picture 1) and Vietnam (picture 2) 34

Figure 2.2: Spheres of women's vulnerability to HIV infection in Indonesia 58

Figure 3.1: Global coverage of PMTCT services in 2016 69

Figure 3.2: A comprehensive HIV-PMTCT 77

Figure 3.3: Health poster 78

Figure 3.4: ARUMI adventure: Searching for information about PMTCT and Family Planning for HIV-positive women (IPPI 2017a) 87

Figure 3.5: The gap between the need of PMTCT services (blue) and accessibility of PMTCT services for pregnant women living with HIV (yellow) 89

Figure 3.6: Referral system of the four pronged-strategy in PMTCT services in South Sumatra, Indonesia 91

Figure 4.1: FPAR cycle of enabling HIV-positive women to access PMTCT services 105

Figure 4.2: A collage showing modes of HIV transmission among women of childbearing age (For explanation of this figure, see Chapter 5) 107

Figure 4.3: Visual outcome: Puppets used for creating a video of an adaptation of a traditional Indonesian song “Cuk Ma Ilang” (Palembang Idiom) 108

Figure 4.4: Data generation cycle of the field research 124

Figure 4.5: Process of creative participatory of creating modified lyrics of Cuk Ma Ilang 127

Figure 4.6: Process of creative participatory of role play 128

Figure 4.7: Puppet show for role play with a group of HIV-positive women 134

Figure 4.8: Research onion diagram to describe the positioning of the research 135

Figure 5.1: How the HIV-positive women in this study believe they contracted HIV (n=18) 155

Figure 5.2: Collective knowledge related to the complexity of HIV transmission among women of childbearing age (Created by Sehati A, April 2017) 156

Figure 5.3: The spider’s web of HIV transmission among heterosexually married women and men in Indonesia 159

Figure 5.4: Multiple layers of factors influencing Indonesian women’s vulnerability to HIV 160

Figure 6.1: Workshop for midwives on PMTCT and HIV screening at Palembang PHO, June 2017 169

Figure 6.2: Barriers to accessing PMTCT services 187

Figure 7.1: Zee’s drawing of a mother goose and her goslings 191

Figure 7.2: Putri's mindmap entitled Kekuatan seorang ibu (The power of a mother) 193

Figure 7.3: Mona’s poster: I am HIV positive 195

Figure 7.4: Adi's drawing entitled 'Living to the full' 195

Figure 7.5: Oda's mapping entitled Ibu Oda Kuat (I am Oda, a strong mother) 196

Figure 7.6: Oda's mindmap of patients' needs of supportive health clinic environments 199

Figure 7.7: Video of Dr Zizi, a senior obstetrician, 'going viral' on Facebook 203

Figure 7.8: HIV posters inside VCT rooms in two hospitals in Palembang 207

Figure 7.9: Simple language for PMTCT services: "Let's protect mothers, children and health workers from HIV" 209

Figure 7.10: Health Promotion poster by Sehati A (six HIV-positive women) 209

Figure 7.11: Four spheres of the elements needed to support women's rights to access PMTCT services 213

Figure 8.1: Paradise lies at the feet of the mother-Surga ditelapak kaki Ibu (Collage by Sehati A, 6 HIV-positive women) 223

Figure 8.2: Women's vulnerability to HIV infection in Indonesia: An Intersectional approach 224

Figure 8.3: HIV-related stigma in Indonesian context (adopted from (Mahajan et al., 2008; Stangl et al., 2019) 228

Figure 9.1 HIV test is not scary (see Cuk Ma Ilang modified lyrics, in Chapter 7)…240

Figure 9.2 A social programme of Rp 10,000 untuk ADHA (movement of "$1 for HIV-positive children") …………………………………………………………253

List of Appendix

Appendix figure D.1: Mind map of fieldwork planning with research facilitators ...335

Appendix figure D.2: Advertisement for individual interviews and focus groups....336

Appendix figure D.3: Creative output: handwritten lyrics of song 343

Appendix figure D.4: Puppet show showing Intan accessing PMTCT services 347

Appendix table C. 1: Previous research applying Feminist Participatory Action Research...333

List of Tables

Table 1.1: HIV prevalence in different groups in Indonesia (population of 270 million) 5

Table 1.2: Health services related to HIV in Palembang 24

Table 3.1: PMTCT global history, 1994-2013..62

Table 3.2: Key players of PMTCT programmes, and their main roles........................67

Table 3.3: Recommended contraceptive methods for HIV-positive women...............79

Table 3.4: Regulations of Ministry of Health (Permenkes) related to Reproductive Health and a comprehensive PMTCT service...82

Table 4.1: Characteristics of the HIV-positive women in this study.........................118

Table 4.2: Characteristics of the midwife participants 121

Table 4.3: Characteristics of the doctor participants...122

Table 4.4: *Characteristics of the NGO worker participants*.....................................122

Table 4.5: Dissemination with HIV policy makers, and health and women's organisations 123

Table 4.6: Fieldwork of data generation in this research 125

Table 4.7: Creative audio-visual outputs produced by 18 HIV-positive mothers 126

Table 4.8: Creative audio-visual outputs produced by other groups in this study.....129

Table 4.9: Rigour checklist in the data analysis 130

Table 5.1: Mawar's timeline 138

Table 5.2: Oneng's timeline..144

Table 5.3: Mira's timeline...149

List of Text-boxes

Text-box 6.1 Ani's story: Difficult access to ARV treatment 171

Text-box 6.2: Anti and Lela: HIV testing procedures for married women and the dilemma about their implementation 180

Text-box 6.3: Adel's story: HIV diagnosis after the delivery 183

Text-box 6.4:Lili's story: Anal sex with her husband 184

Text-box 7.1: Scene 5: Role Play by Sehati B (a group of six HIV-positive women) 200

Text-box 7.2: Text for a video to create awareness among health workers of the need to embrace pregnant women living with HIV (Dr Zizi) 201

Text-box 7.3: Inilah Suara Bidan Wong Kito Galo 204

Text-box 7.4: Scene 4: Role Play by Sehati B 205

Text-box 7.5: Modified poems with theme of "Communication, information, and education" by five NGO workers...207

Text-box 7.6: I am HIV positive and pregnant 212

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed: Date: 11 October 2019

Opening words

On my journey of being an epidemiologist and statistician, I learned about communicable diseases, including HIV. I know the risk factors associated with HIV, methods of prevention, and the disease history of HIV in human body. Mostly however, I know discussion about HIV are about numbers, risk ratios, prevalence and incidence rates, and other epidemiological calculations. Most of the books I have written about epidemiology and statistics in health are in the Indonesian language: Epidemiology for Public Health Student (2015, best seller), Epidemiology of Communicable Diseases (2016) and Statistics in Health-Application of SPSS and Stata (2017).

This Ph.D. journey provides me a different perspective of being an epidemiologist. My supervisors challenged me to take a different approach to understand this world through a qualitative methodology using Feminist Participatory Action Research. Retrospectively, at the end of my doctoral journey, honestly, in the first stages of my Ph.D., I was a bit disappointed as I did not apply my epidemiological and statistics skills. I was required to learn many new skills in this qualitative world. My supervisors said they would supervise me step by step, so I took a deep breath and went home for this final decision about my methodology and told my husband about my decision. My husband added his support, saying, “It is time to learn new things, honey, no need to cry, you can go as far as your supervisors will take you. Please, see our little kids fly from thousands of miles away from Indonesia to support you”.

I started to reflect on the benefits of my own journey using a qualitative approach under their intensive supervision. I learned the importance of ownership of the research process for my participants and myself. I wrote my dissertation with my heart, and with tears, some joyful, for being able to make a change for my country, Indonesia, the largest Muslim country in the world and the fourth most populous nation worldwide. This Ph.D. journey, almost four years, was challenging, but this process was eye-opening for me as a public health researcher usually working in a positivism paradigm. It is beyond writing a questionnaire, analysing using statistics tools (SPSS or Stata) and interpreting the numbers using the research skills that I applied in the last decade. I am Najmah–a positivist researcher, an epidemiologist and statistician, and now a novice practitioner of feminist and participatory action research.

Acknowledgements

This thesis would not have been possible without my supervisors, Dr Sari Andajani and Associate Professor Sharyn Graham Davies. They worked very hard with me and made sure my work met the high standards expected by Auckland University of Technology (AUT). They never gave up on me. The first question that they usually asked during our meeting, was "How about your kids?" (*gimana anak-anak*?) if I did not bring them to my meetings. It is *Whanau*'s (Maori: Extended Family) Journey; even my eldest kid always called my supervisors "my mummy's mothers". When I was confused, you were tireless supervisors to guide me through this new world. Thank you so much for your support and encouragement.

I am always concerned that New Zealand (NZ) Scholarship, from the Ministry of Foreign Affairs and Trade (MFAT), provides part of my scholarship funding from taxes, which are paid by people living in New Zealand. All officers for this NZ scholarship are amazing at AUT: Sacha Pointon, Margaret Leniston, Ruth O'Sullivan, Prerna Taneja, Sandelyn Agnes Su Kuan Lua, and Yuri Kimani. They knew me as a scholar, a mother, and a wife during my four years gaining expertise in New Zealand. It is helpful if your scholarship officers understand about the expectations of women in different cultures from different countries. After my fieldwork, when I was eight months pregnant, I came to the scholarship office with my worry that they would ask me to go home to Indonesia and take maternity leave for six months or more. Surprisingly, the NZ officers in AUT gave me congratulations and hugs, then one of them said, let's talk about pregnancy, study and maternity leave, without leaving Auckland. I would like to express my gratitude for their contribution and this chance for studying in New Zealand.

My wholehearted thanks also go to Margaret Leniston, who transferred her knowledge about gender and feminism, checked my writing, became a grandmother for my kids in Auckland, and went way beyond her role of a scholarship advisor in AUT. She invited my family to her house and provided a delicious lunch for my family, the day after the darkest day in New Zealand for Muslim communities in Christchurch: 15th March 2019. She kept her eyes on my work from when I started my study to the end of my study. I love you, mum.

I will never forget the 18 HIV-positive mothers who opened their hearts and shared their aspirations with me. I would like to thank them all for their contributions to construct new knowledge and for helping to create solutions for what women need for better access of PMTCT services. I also thank them for teaching me to think humanly and work ethically as a researcher. I am also in debt to other groups of health workers: NGO workers, and policymakers related to PMTCT services and HIV who involved in this study. These groups listened to the aspirations of HIV-positive women and provided further insiders' perspectives to fill the gap in knowledge for improving access to PMTCT services. Also, I am really grateful for suggestions about working in the field which came from my research advisory groups from local non-governmental organisations, the Public Health Office of Palembang, and the AIDS commission of Palembang.

I am really grateful for the love and support from my family. With the deepest respects for my deceased mother, Enni Erosa, who had a big ambition for her daughter to pursue an education when she did not have a chance to reach her own ambitions. I remember what my mother said to me, one week before she passed away, that "I was a smart mother, wasn't I? I only provided (*membekali*) all my children, daughters and sons, with an equal chance for higher education" (Enni Erosa, personal communication, December, 2010). To my father, Usman Nurdin, thank you for being a grandfather and grandmother to your grandchildren, who now will never see their grandmother. I always thank him, and my mother, for letting me pursue my master's degree in epidemiologist and biostatistics at the University of Melbourne (2008-2009) with an Australian Partnership Scholarship, before my marriage. This first chance of going overseas opened chances to pursue my short course in KIT with the Netherlands Fellowship Partnership (NFP) in 2012 and my Ph.D. with a New Zealand Scholarship in 2015, along with my nuclear family.

Many thanks to my husband, Kusnan Sayuti, who has worked very hard to support his wife and children, financially and psychologically, and been a super dad for our three little children. We started our journey with two toddlers, Queency Qoryra Himada (2 years), Maitreya Adilla Sultanah (6 months), then our third baby, Muhandas Elthamis Haroki, was born in Auckland after my fieldwork. My husband was aware that MFAT scholarship did not cover our family needs in Auckland. He left his prestigious position 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.

My examiners during my first year, Dr Cath Conn and Prof Eleanor Holroyd, still provided their time for on-going discussions during my Ph.D. I would like to say heap gratitude for great feedbacks from Associate Professor Linda Bennett and Professor Siriporn Chirawatkul in my final examination. Also thank you for the encouragement of all of my friends: Dr Stenly Hely Sajow, Lisa Waldner, PhD. Candidate, Dr Sansanee Chanthasukh, Dr Dinar Lubis, Dr Shabnam Jalili-Moghaddam, Dr Carol Maibvisira, and Dr Hani Yulindrasari, and other friends who supported my journey in understanding this new knowledge. Whole heartedly, I give you my thanks.

Thank you also to all the leaders that showed kindness to me in permitting me to study overseas, undertaking my master’s and my doctoral degrees, at my young age. They are: 1) my rectors at Sriwijaya University, Prof. Dr Badia Perizade, MBA (2007-2015) and Prof Dr Ir. H. Anis Saggaf, MSCE (2016 to the present) and vice rectors; 2) the dean of the Public Health Faculty, Hamzah Hasyim, Ph.D. Candidate (2011-2016) and Iwan Stiabudi, SKM, M.Kes. (2016 to the present) and vice deans; and 3) the Head of Public Health Programme, Dr Husnil Farouk, MPH (2006-2010) and dean of the Faculty of Public Health, Prof Dr Zarkasih Anwar, SpA. (2006-2010) and all the staff, such as Radesman, Ima Fransiska, Fernando Putra, and Dessy Dastini at *Universitas Sriwijaya*, South Sumatra, Indonesia. All the best.

All my friends and families on Facebook, you are part of my support, listening and reading our stories, and giving likes and comments about the journey of *PhD Emak Wong Palembang* (PhD Mum from Palembang). It is just the beginning, to motivate other Indonesian women and for our female generation, to pursue their educations. Wait for our novel, *Autumn sekali lagi* (Autumn, one more time).

Finally, for my friends, mothers surrounding me, Railways mothers, Uzma (Pakistan), Nurul Fitriah, and Nurhayati Saputra (Indonesian mothers), and other Indonesian women, thank you for helping me by taking care of my kids when I needed my own time to study and/or for sharing your delicious foods with my family. For my best friend, Zaiton Rahim (Malaysia), thank you to maintain my well-being with your traditional massage to recover my severe back pain and ankle sprain during my study, you save my life. In particular, the teachers of my kids in the childhood centre at First Steps and at AUT, and the Parnell School, thank you for educating my children, when I did not have enough time to focus on their character building during my study. I am in debt to all my kids' teachers so much.

For my proof-readers during my Ph.D. journey, Katie Coluccio, Shoba Nayar Ph.D., and Associate Professor Jill Poulston, thank you for helping me write this thesis in correct English.

Without these contributions, there would be no Najmah in this social and academic position. Thank you.

This dissertation, "My baby deserves love, not HIV", I dedicate to all the mothers and wives in Indonesia.

Auckland (New Zealand) and Palembang (Indonesia),

October 2015-October 2019

My *Whanau* Journey with my beloved husband and children

Ethics Approval

The Auckland University of Technology Ethic Committee (AUTEC) and Sriwijaya University approved this research on 7 March 2017 and 15 March 2017, AUTEC reference no 17/22 and Committee of the Faculty of Medicine of Sriwijaya University, reference No. 39/keprsmhfkunsri/2017 (see Appendix A).

Chapter 1. Introduction

This chapter presents an overview of the research topic and significance of the study. The process of developing the research topic is described, as well as my position as a researcher from Indonesia, a mother and an HIV-negative pregnant woman during my fieldwork. The chapter is divided into ten main sections: prologue, background to the study, research gap, research aims and questions, why I came to focus on HIV, overview of key groups for HIV programmes in Indonesia, the field site: Palembang (the capital city of South Sumatra), my positioning as a researcher, the significance of the study, and the structure of the thesis. I will discuss each in turn.

1. Prologue

The prologue starts with a letter emailed to me by Mona, an HIV-positive woman who was 30 years old, and one of the 18 participants in my study. I felt humbled that Mona had opened up her life to me. Mona's letter reflects the multifaceted challenges of an HIV-positive woman. She contracted HIV from her ex-husband, then continued her life with her daughter, and later remarried an HIV-negative man.

Honestly, I haven't been writing for a long time
When I am sad, I wanted to write again
Deep down I am always grateful for all blessings in my life
I hope my share is meaningful to you, readers

In November 2012…
My husband was sick, he got AIDS
He lied to me of his past…
Using injecting drugs….
In December 2012…
I found out that I was also HIV positive, but my daughter is negative
I was sad….
I hate everything in my life
It was the most difficult thing that I have ever had in my life….
It was hard to accept this curse
My husband died in the same month
He said 'sorry' in his last breath

I was ostracized by my laws
I felt different, discriminated, and hurt
I want to end my life…
My husband's family wanted to take away my only child…

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 the complexities of their situations. I was also aware that they became confident citizens through this research, and their voices were conveyed authentically.

The research methodology used in this study, Feminist-Participatory Action Research (FPAR), created an active opportunity for Mona and many other participants to feel empowered to understand, analyse, and express their feelings about their personal situations, the stigma attached to HIV, and the gendered relations in their marriages. FPAR made it possible for my participants to take action to overcome barriers and access PMTCT services to improve both their own and their children's health outcomes, and inspire other Indonesian and HIV-positive women to access these services.

In this prologue, I have introduced my research and some of the key terms used in my study. The next section provides more context to the study.

2. Background to the study

> Angrily I asked the doctor "How come my daughter got this HIV?" The doctor replied Bu (Madam), you should know better than me how HIV was transmitted to your daughter (Oneng, an HIV-positive widow with six children. Her youngest child is HIV-positive).

Many women aspire to be mothers and want children, including women living with HIV (WLWH). Pregnancy occurs among WLWH in Indonesia (Anindita & Shaluhiyah, 2016; Hidayana & Tenni, 2015; Ismail et al., 2018; Rahmalia et al., 2015), and there is a risk of HIV transmission from mother to child through the mother's pregnancy, delivery, and/or breastfeeding [Indonesian Ministry of Health (MoH) (MoH, 2013c, 2015b)]. In my research, mothers and wives (in Indonesian, referred to as "*ibu rumah tangga"*) were a key concern. These women learned of their HIV status after their husband or children got sick or died, as was the case for Mona and Oneng.

This section considers the alarming increase in HIV among *ibu rumah tangga* in the general population, followed increasingly by the children who are primarily infected by their HIV-positive mothers. This section also discusses the importance of PMTCT services, and the challenges related to access of PMTCT services in Indonesia.

HIV among ibu rumah tangga

To provide a global context, the HIV epidemic in the Asian region is categorised as a concentrated HIV epidemic, in which HIV prevalence in the wider population is below one percent, except in key populations where it is over five percent (UNAIDS, 2013; Figure 1.1). It differs from sub-Saharan Africa, where the HIV epidemic is categorised as a generalised epidemic, meaning HIV prevalence in the wider population is over one percent. Indonesia is the third highest burden in terms of HIV in Asia; in South-East Asia, Indonesia is ranked highest for HIV infections (Pendse, Gupta, Yu, & Sarkar, 2016; UNAIDS, 2013; WHO, 2012). While other countries in the Asia and Pacific and South-East Asia show a decreasing trend of new HIV infections, Indonesia tend to have an increasing trend of HIV cases every year (UNAIDS, 2013; WHO, 2012).

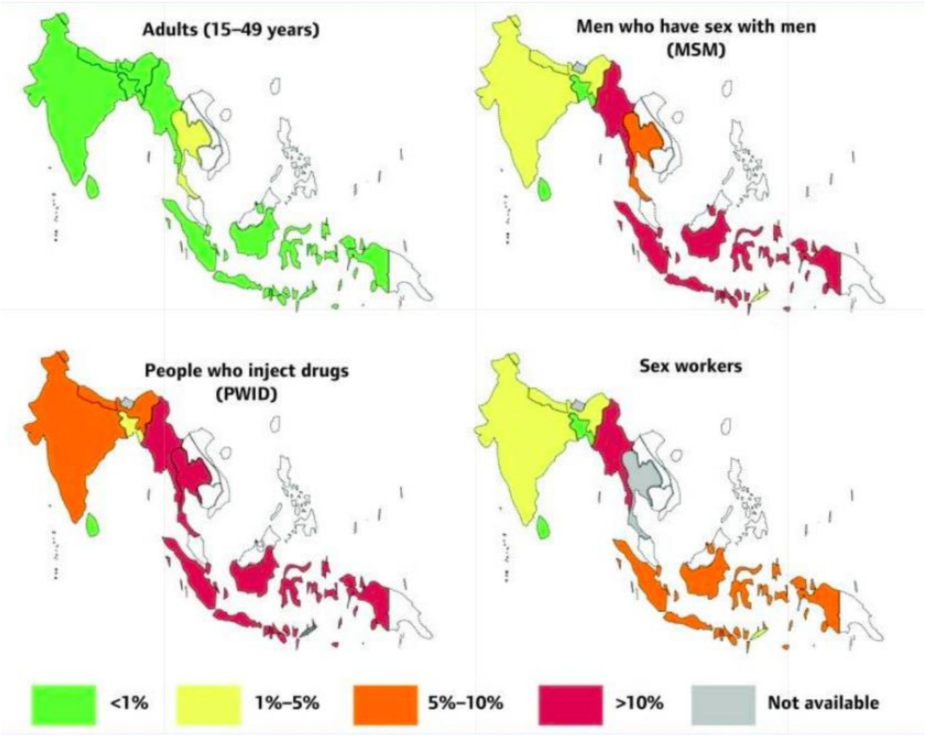


Figure 1.1: HIV prevalence among adults (15-49 years) and key populations in South-East Asia

Note: Reprinted from *HIV/AIDS in the South-East Asia region: progress and challenges*, by Pendse, Gupta, Yu, & Sarkar, Bethesda, 2016, USA. Copyright (2016) by Pendse, Gupta, Yu, & Sarkar.

Note. Except for Papua, Indonesia, HIV in the wider population is > 1 %.

In Indonesia, HIV prevalence is low, at about 0.4% of the total population (Table 1.1); the exception is in the province of Papua, where around 2.3% are HIV-positive (MoH, 2015b). Of the 34 provinces in Indonesia, West Papua, Jakarta, and Bali have the highest prevalence of

HIV. A recent report noted that 280,623 people had HIV, and 102,667 were diagnosed with Acquired Immunodeficiency Syndrome (AIDS) in Indonesia over a period of 20 years (MoH, 2018). In 2018, the incidence numbers of HIV and AIDS reached 48,300 and 9,280 respectively. Indeed, the Indonesian MoH (2018) reported an alarming annual trend of HIV and AIDS infections in women; in every 10 new HIV cases in Indonesia, four were women of reproductive age and six were men.

Table 1.1: HIV prevalence in different groups in Indonesia (population of 270 million)

	Prevalence Risk	Estimated number PLWHIV$^{1)}$/high risk groups$^{2)}$
General population		
All adults aged 15 and over	0.4 %	620,000$^{1)}$
Women	0.3 %	220,000$^{1)}$
Men	0.5%	420,000$^{1)}$
High-risk group		
Injecting drug users	28.8 %	33,500$^{2)}$
Men having sex with men	25.8 %	754,300$^{2)}$
Female sex workers	7.2 %	226,800$^{2)}$
Transgender	24.8 %	38,900$^{2)}$
Men access prostitutes	-	5,244,064$^{2)}$

Source: (MoH, 2017; UNAIDS, 2019, 2020)

Note: $^{2)}$ estimated number of high risk groups to contracted HIV (not all HIV-positive); Prevalence risk of HIV in the general population in Papua > 4

Each year, on World AIDS Day (1st December), national attention is drawn to an increased prevalence of HIV among *ibu rumah tangga* in Indonesia, including those in Palembang, the research site (Anugerah, 2015; Firmansyah, 2015; Maharani, 2017; Najmah, 2017; Tambunan, 2015; Triansyah, 2015; Wibawa, 2017). According to MoH data, there has been a rapid increase of reported cases in the last 10 years amongst women aged 15-49 years in Indonesia. The number of new HIV cases among women rose from 3,565 HIV cases in 2008, to 9,318 cases in 2012; in 2017, and increased fivefold to 17,579. Of note, the highest cumulative number of late stage HIV infections (AIDS) in women, was amongst those categorised (based on their work), as *ibu rumah tangga* for more than a decade (at 14,721 cases), fivefold higher than that of sex workers (at 3,314 cases) (MoH, 2018).

Pregnancy occurs among women with HIV. The Indonesian MoH (2013c) indicated that HIV prevalence among pregnant women in Indonesia (excluding Papua) is about 12,760 (0.25% of

5,104,260) and increasing annually. This figure is 15 times higher in Papua, with 3,166 out of 87,230 (3.36%) of all pregnant women living with HIV (MoH, 2013). The number of pregnant women with HIV increased by 25% in 2016, from 15,517 in 2012 to 19,636 cases (2013c). The increasing number of HIV cases among *ibu rumah tangga*, is strongly associated with the increasing number of pregnant women with HIV as well as HIV-infected children (0-14 years).

HIV among children

Babies born to HIV-positive mothers are at risk of contracting HIV. Globally over 90% of newly HIV-infected young children have the virus transmitted from their mothers (Ishikawa et al., 2011; MoH, 2015b; WHO, 2010, 2019b). Without any preventive interventions to reduce the transmission of HIV from mothers to children, research indicates that between two and five babies born to every ten HIV-positive pregnant women are more likely to contract HIV through the mother's pregnancy, labour and/or breastfeeding (De Cock et al., 2000; MoH, 2013a; Tudor Car et al., 2011). Furthermore, half of these children living with HIV are likely to die before the age of two if they do not have anti-retroviral treatment (ARV) (MoH, 2015b; UNAIDS, 2016). In the Asian Pacific region, three in four AIDS related deaths in children occurred before the age of five years in 2017, suggesting late diagnoses and treatment for children with HIV, including those in Indonesia (UNICEF, 2018).

There are different estimations of numbers of children with HIV in Indonesia. According to the World Bank (2019), between 2015-2017 there were an estimated 3,000 newly infected-HIV children (0-14 years) annually in Indonesia. However, reported cases of HIV among children numbered only about 1,000 cases at that time[1], indicating many undetected HIV cases in Indonesian children (MoH, 2018). UNICEF noted that in 2017, Indonesia was amongst the countries in East Asia and the Pacific region with the highest population of children living with HIV (29,000), followed by Myanmar and Thailand, at 16,000, and 9,600 respectively (UNICEF, 2018).

---

[1] According to one participant (Dr Zizi), an HIV specialist, the HIV phenomenon is like a "shark phenomenon"; "we only can see the shark fin above the water surface, but the big body of the shark is submerged under the water surface." Dr Zizi estimated that one symptomatic HIV may represent 30-100 asymptomatic HIV infections. In Indonesia, the HIV among children could therefore be about 30,000 to 100,000 cases, if the reported cases are about 1000.

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 between 2004-2008, including services at Palembang (MoH, 2012a)[2]. PMTCT services were initially introduced primarily in regions with high HIV prevalence, such as Jakarta, West Java, East Java, Papua, and Bali (MoH, 2012a). PMTCT services had spread to other Indonesian provinces. Approximately 378 PMTCT service centres were established in Indonesia by 2013; 108 were based at public hospitals, and the rest were at community health centres *(puskesmas)*. At least one public hospital in each province was designated as a provider of PMTCT services (MoH, 2015b). Palembang city, the field site of my study, has two PMTCT services; one is located at a public hospital, and the other, at a private hospital (see Palembang: Health sector in this chapter).

The 2012 report on PMTCT coverage in Indonesia reported a relatively low mother-to-child HIV transmission (MoH, 2013c). For example, 1,329 of 43,624 pregnant women in the general population who accessed antenatal HIV testing were confirmed as HIV positive (MoH, 2013c). Of these 1,329 HIV-positive pregnant women, 1,070 (80%) received ARV therapy and 1,145 babies (86 %) from HIV-positive mothers received prophylactic therapy, yielding only 86 HIV-infected babies and a relatively low risk of mother-to-child HIV transmission (7.5%) (MoH, 2013c). Without any intervention, it was estimated that about 256 to 765 babies would be born with HIV, based on the percentage of 20-50% HIV risk for babies born to HIV-positive mothers. In contrast, by accessing PMTCT intervention, the risk of HIV to infants reduced to only 86 children born with HIV from the 1,329 HIV-infected pregnant women. No data since the 2012 report were available at the time of this study.

Access to PMTCT services, nevertheless, is very low in Indonesia. For example, between 2012 and 2016, less than 10% or 1000-1600 of all HIV-positive pregnant women (estimated at 10,000-16,000) accessed PMTCT services, yielding a high number of children at risk of contracting HIV through vertical transmission (MoH, 2013c). Recent reports from UNAIDS also show the urgent need for Indonesia, one of 23 priority countries offering PMTCT services, to focus on enhancing access to PMTCT services. Figure *1.2* shows how Indonesia lags well behind other countries in sub-Saharan Africa in providing women access to ARVs. While countries such as Namibia, Uganda, and South Africa show high rates of women accessing

---

[2] PMTCT was introduced in sub-Saharan Africa between the early and mid-2000s after global initiation of PMTCT services between 2000 and 2005 (Hampanda, 2012; Idele et al., 2017). In Southeast Asia, Thailand was the first country to adopt PMTCT programmes and develop its country-based-research for effective biomedical treatment for PMTCT (Phanuphak & Phanuphak, 2016) (see Chapter 3).

ARVs for PMTCT (at 95%), Indonesia falls behind with only 14% of HIV-positive pregnant women accessing ARVs for PMTCT. Thus, the concern of this research is how to better enable HIV-positive Indonesian women to access PMTCT services (UNAIDS, 2017).

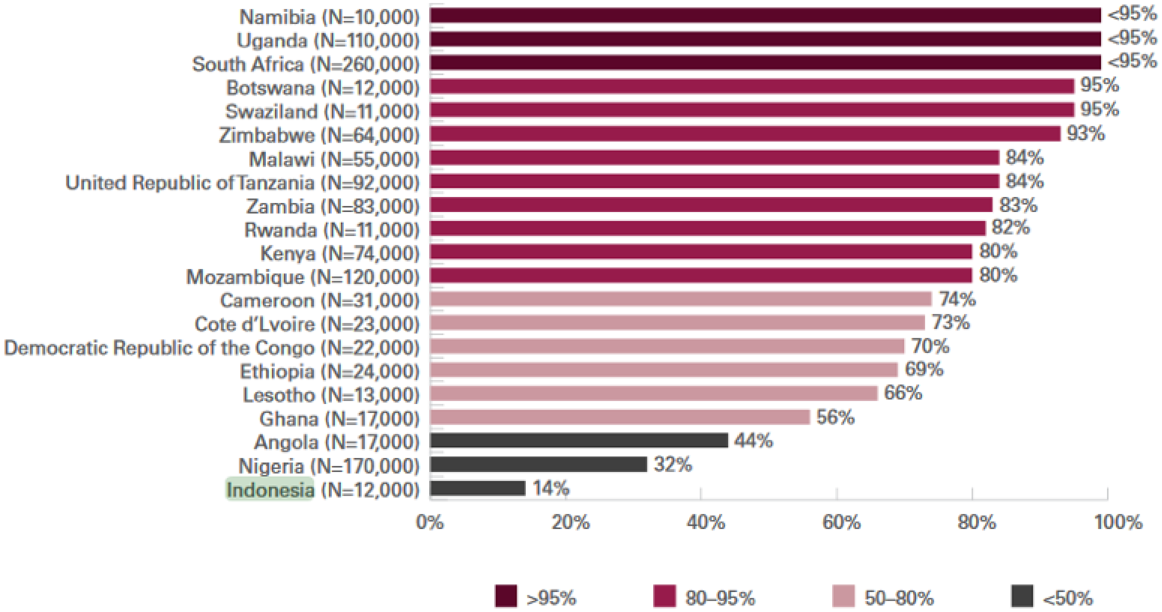


Figure 1.2: Percentage of HIV-positive pregnant women in 2016 receiving effective ARV for PMTCT in countries with at least 10,000 HIV-positive pregnant women

Note: Reprinted from UNAIDS estimates by UNAIDS, 2017, Geneva. Copyright (2017) by UNAIDS.

Note. Selected countries include those for which data were available and in which an estimated minimum of 10,000 pregnant women were living with HIV in 2016.

3. Research gap

Recent research on HIV in Indonesia has focused on three major themes: 1) HIV vulnerability among Indonesian women; 2) experiences in accessing HIV care; and 3) barriers to accessing PMTCT services. However, there is a gap in the extant research. Firstly, with the exception of recent quantitative analyses by Rahmalia et al. (2015) and qualitative research by Butt (2015), research on the complexity of HIV vulnerability amongst Indonesian women is limited. Secondly, enquiries into HIV-positive women and their experiences in accessing HIV care in Indonesia have tended to focus on high-prevalence provinces such as Jakarta, West Jawa, Bali and Papua, with the exception of a study by Samuels (2018) conducted in Aceh, a province in Sumatra. Thirdly, strategies to enable HIV-positive women to access PMTCT services remain under- explored in the Indonesian and global context, with the exception of qualitative research by Badriah, Tahangnacca, Alkaff, Abe, and Hanifah (2018) and Hidayana and Tenni (2015) in

Jakarta and West Jawa respectively, Lumbantoruan, Kermode, Giyai, Ang, and Kelaher (2018) and Munro and McIntyre (2015) in Papua, whose research focussed on barriers to accessing PMTCT services. In addition, there is little belief within the health services, programmes, and research, that HIV-positive women are the real knowers of their lived reality, problems, and the solutions that could enable them to access PMTCT services. Although Butt (2015) and Bennett (2015) considered HIV-positive women's voices, they did not specifically focus on PMTCT services; furthermore, Bennett particularly focussed on Sexually Transmitted Infections (STIs), and not HIV. The current study therefore makes a key contribution by filling this gap in the research.

This study contributes to an emerging body of research and is largely informed by the belief that HIV-positive women have the capacity to offer relevant and meaningful solutions to improve PMTCT programmes in Indonesia. The study extends the work in previous studies in five main ways. Firstly, this research has created a space for opening dialogue, building trusting partnerships, and providing participants with a choice of creative methods to generate rich data and construct knowledge relating to the study's focus. Secondly, during my field work, I talked directly with HIV-positive women, including pregnant women with HIV and some of their husbands. I also met with some HIV-positive children; to date, no other researcher has done this. Thirdly, the research setting was conducted in a low HIV prevalence province, Palembang, the capital city of South Sumatra. Previous research has mostly considered high-prevalence provinces. Fourthly, my insider and outsider position privileged data collection, as I was a local female researcher, a mother, and pregnant during my field work. I am also a lecturer in an Indonesian public university, with the ability to utilise the knowledge gained to advance improvements in services. Finally, this study contributes to making initial changes to create a critical consciousness and a social transformation by linking the aspirations of HIV-positive women to groups involved in the provision of PMTCT services, such as NGO workers, health workers, and various HIV stakeholders.

4. Aim of this study

The two primary aims of this study were:

1. To provide a safe but critical collective space for HIV-positive women to reflect on and make meaning of their experience in maternal health and PMTCT services; and
2. To invite HIV-positive women to take part in finding solutions to current problems faced when accessing PMTCT services, and how such services could be improved to meet their needs, aspirations, and ideals.

The following research questions were formulated to best achieve the research aims:

1. What factors activate HIV-positive women to access PMTCT services?
2. How can HIV-positive women be enabled to develop strategies for the best access to PMTCT services?
3. How can these strategies be activated?

This research was conducted within the constraints implicit in a socially and culturally stigmatised HIV disease; a disease that is a sensitive, shameful, and taboo topic in Indonesian society. The research recognised the difficulties of reaching HIV-positive women and invited them to be change agents for halting mother-to-child transmission of HIV in Palembang, Indonesia. The research methodology particularly facilitated their engagement with the research and helped them become empowered to make decisions impacting on their health outcomes and reducing HIV risk to their children.

5. Why I came to focus on HIV

The idea for my Ph.D. study emerged from my research experience with IDUs in Palembang, South Sumatra in 2010. One of my research assistants, a former IDU and HIV-positive person, recalled a story of his peer (pseudonym ‘Riko’) and his wife’s (pseudonym ‘Lasmi’) experience accessing PMTCT services in a public hospital in Palembang. Lasmi, a public servant, was infected with HIV from Riko, a former IDU. When Lasmi delivered her baby, Riko was asked by a health worker to cut the umbilical cord of their baby as the workers did not want to do it themselves due to their perceived self-risk of contracting HIV. He also witnessed how their baby was treated differently in that hospital. Riko told my research facilitator that he regretted accessing PMTCT services. I asked myself, “was it true that stigma and discrimination still occurred in health settings?” “Could I believe Riko’s story that was recalled by my research 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.

My Ph.D. research journey (2015-2019) was seen to have the potential to generate new knowledge related to HIV-positive women and their access to PMTCT services in Indonesia. My research invited HIV-infected women, individually and collectively, as well as peer support workers from NGOs and health workers related to maternal health and PMTCT services, to share their experiences through creative participatory and visual methods, and provide solutions to problems regarding utilisation of PMTCT services in Palembang. I was guided by the work of Patricia Maguire (1987, 1996, 2006), Brinton Lykes (2007; 2014; 2012), and Collen Reid and Wendy Frisby (2008) on the use of FPAR, in which women's voices, aspirations, and ideas are central to the study. Details on the aetiology and application of the FPAR methodology are discussed in Chapter 4.

6. Overview of key groups for HIV programmes in Indonesia

Indonesia's first HIV case was found in Jakarta, in 1983, in a transgender individual. This case was followed by three AIDS cases in 1984 and one AIDS case in a tourist from the Netherlands in 1987 (Riono & Jazant, 2004; Yayasan Spritia, 2014). At that time, HIV among female sex workers was very low (about 0.03% among 40,000 female sex workers) (Praptoraharjo, Suharni, Pudhiati, Dewi, & Safika, 2016a; Riono & Jazant, 2004). Around 2000, however, there was a marked increase in HIV rates in injecting drug users (IDUs). One in every two IDUs was HIV positive, and this was believed to contribute to the increase of HIV among female sex workers (Praptoraharjo, et al., 2016a; Riono & Jazant, 2004).

Post-2000, HIV programmes in Indonesia were highly concentrated on IDUs and female sex workers. HIV was contextualised as the "hooker disease" or *penyakit pada populasi kunci* (Imelda, 2015, p. 5). Female sex workers were condemned as the main actors in the spread of HIV and were heavily targeted by HIV and STI prevention, testing and treatment service providers, so that men who were clients of female sex workers could be protected from HIV transmission (Imelda, 2014; Pisani, 2010; Praptoraharjo et al., 2016a; Praptoraharjo, Suharni, Pudhiati, Dewi, & Safika, 2016b). However, there has been a decrease of HIV prevalence amongst female sex workers in brothels between 2007 and 2013 [Indonesian National Aids Commission (INAC), (2018; MoH, 2014a)].

In the 21st century, specifically in the last decade, the number of women in the general population has increased in Indonesia (MoH, 2018). Among the general population, women are more vulnerable and susceptible to contracting HIV and other STIs, compared to men in heterosexual relationships (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013; Brawner, 2014; Higgins, Hoffman, & Dworkin, 2010; Lin, McElmurry, & Christiansen, 2007; Ostrach & Singer, 2012). Among sero-discordant couples (in which one partner is HIV-positive), women are more than two times as likely as men to become HIV infected. Women are also more likely to have undetected STIs, which is a one risk factor for getting infected of HIV (Higgins et al., 2010), further will be discussed in Chapter 3.

HIV transmission amongst heterosexual, as well as homosexual men (men having sex with men, or MSM), has been the primary contributor to the fast growth of HIV, and may link HIV high risk groups to the wider population, such as *ibu rumah tangga*, through unsafe sexual practices (Damar & du Plessis, 2010; Imelda, 2014; Ismail et al., 2018; MoH, 2012b; Rahmalia et al., 2015; Riono & Jazant, 2004; Samuels, 2018; Stephen, 2015; Sukmaningrum, 2015). For example, a 2011 report from the Indonesian MoH (2012b) shows as many as five million women in Indonesia were married to men who were vulnerable to HIV infection at that time. Figure *1.3* illustrates the recent complexity of patterns of HIV infection affecting heterosexual married women and men. Those male sex partners or husbands might have used intravenous drugs or had unsafe sex with an HIV infected female sex worker or were bisexual (MoH, 2012b; Sakti, 2015).

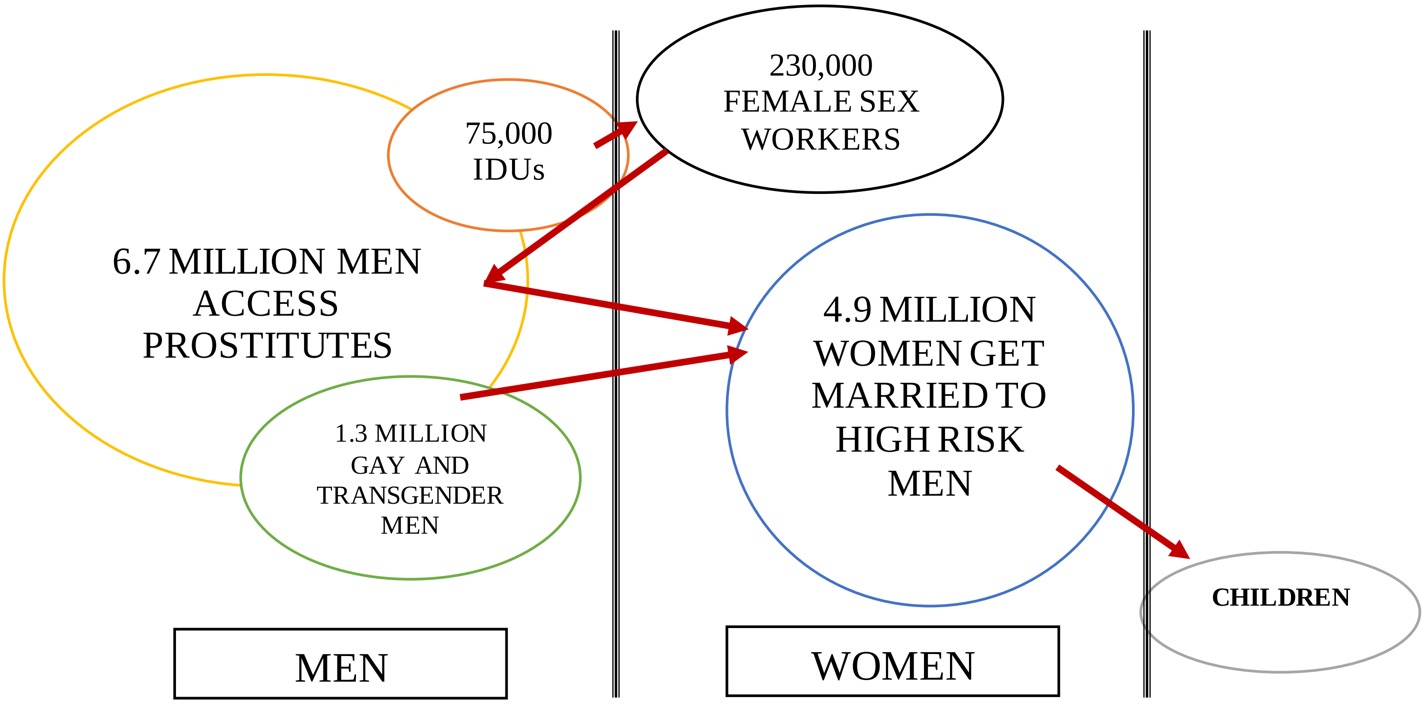


Figure 1.3: HIV Vulnerability among married women in Indonesia.

Note: Reprinted from Ministry of Health, translated by Najmah. Copyright (2012) by Ministry of Health.

Note. Of 6.7 million men who accessed prostitutes, about 1.3 million were also gay or transgender, and around 75,000 were IDUs. Approximately 4.9 million women in Indonesia are likely to marry one of these men. Data in Figure *1.3*, nevertheless, reflect the assumption that married women are not responsible for spreading HIV, as they are considered susceptible to contracting HIV from partners who are exposed to high-risk behaviours related to HIV (See discussion on how women have become key in HIV transmission either to male sexual partners or children, in Figure *5.3* and Figure 5.4 in Chapter 5).

Data produced by the Integrated Biological and Behavioural Survey (IBBS) show that HIV prevalence in key populations has not been well controlled, and fluctuates, which may indicate the failure of controlling HIV in IDUs, sex workers, and transgender people, and account for the under-reported deaths of people living with HIV/AIDS (PLWHIV) in these key groups. Yet, HIV prevalence in MSM has increased (nearly fourfold) from 1.9% to 7.4% (INAC, 2018; MoH, 2014a). Until there was evidence of MSM and HIV in Indonesia, men were “blame free” and women bore the blame for HIV transmission. This moral gender judgement reinforced by Islamic values and government policies, is evidence of the gender discrimination and cultural moral judgements that exist between women and men in Indonesia. This may result in HIV transmission to *ibu rumah tangga* if husbands are exposed to risky behaviours.

HIV infection among women is the result of complex factors. Thus, further understanding is urgently needed, of why women are more susceptible to contract HIV from their HIV-positive husbands than are men from their HIV-positive wives, to contracting HIV, particularly among *ibu rumah tangga*. This will be discussed in Chapter 2. Next, I explain the setting of this research.

7. The Field Site: Palembang, the capital city of South Sumatra

This sub-section is divided into six parts. They are: 1) Indonesia: an overview; 2) Indonesia: snapshot of Indonesia women’s status and societal expectation; 3) Palembang (research area): socio-demographic profile; 5) Palembang: health sectors, and 6) Palembang: HIV prevalence and services.

Indonesia: An overview

This first sub-section provides an overview of Indonesia and Palembang, my research setting. Indonesia is categorised as an emerging middle-income country, and the world’s fourth most populous nation, with 260 million people. Indonesia consists of five large islands (Sumatra, 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, or 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).

South Sumatra is one of 10 provinces in Sumatra, and Palembang is the capital city (Statistics of Indonesia, 2018). South Sumatra is also known as Sriwijaya Land or *Bumi Sriwijaya*. Historically, the name is associated with the Sriwijaya (Srivijaya) Empire, a prosperous maritime empire from the 7th to 12th century that dominated Sumatra island and the Malay Peninsula (Malaysia and Singapura). Population growth in South Sumatra was the third fastest in Sumatra 2015, and is predicted to be Sumatra's second most populous province by 2025 (Statistics of Indonesia, 2018).

In recent decades, South Sumatra, with the capital city of Palembang, was one of Indonesia's busiest provinces, hosting important national and international events, the latest being the Asian Games in 2018, with participants from more than 40 countries. Previous events held in South Sumatra include the Southeast Asian Games (SEAGAMES) in 2011, the Association of South East Asian Nations (ASEAN) University Games in 2014, and the International Al Qur'an recitation in 2014 (Fahlevi, 2015). Additionally, this province has rich natural resources, such as oil, gold, coal, and rubber plantations that have attracted national and international investors both in the past and in the present (Statistics of Indonesia, 2018; Marsden, 1788).

Indonesia: Snapshots of Indonesian women's status and expectations

This second sub-section provides an overview of women's health, education, working space, and political leadership among women in Indonesia. I discuss the challenges of high maternal mortality rates, literacy levels, opportunities for work outside home, and leadership among Indonesian women.

At the national level, the ratio of health workers to the wider population has increased; however, the ratio of skilled health workers (physician/midwives/nurses) to the wider population is still far below desired thresholds. Indonesian's physician ratio of 0.25 with a range of 0.20 in Maluku-NTT-Papua to 0.44 in Sumatra and Sulawesi per 1000 population or less than fifty health workers to provide health services per 100,000 populations; Indonesian's midwives and nurses ratio is between 0.20 to 1.40 and 0.5 to 2 per 1000 people (or between 20 to 200 health workers per 100,000 populations who require professional health treatments) (Mahendradhata et al., 2017). WHO recommended a threshold of 4.45 skilled health workers (physicians and nurses/midwives) per 1000 people to meet health needs, in order to achieve universal health coverage and sustainable development goals (WHO, 2016).

Disparity of access to quality health services may impact on the high maternal mortality rate (MMR) in Indonesia, where the MMR is about 126 mothers in 100,000 live births. Indonesian's maternal mortality rate is lower than that of Afghanistan (396 mothers in 100,000 live births), and of Asia and East Timor (215 mothers in 100,000 live births) but is higher than that of neighbouring countries, such as Thailand, Malaysia and Singapore at 40, 20, and 10 mothers per 100,000 live births respectively (Index Mundi, 2018). Nevertheless, the estimated rate might be underestimated due to unreported mothers' deaths and disparities of integrated health information systems among healthcare providers and public health offices in Indonesia (MoH & UNFPA, 2012). High MMR and infant mortality rates may also become significant barriers to the prevention mother to child transmission of HIV.

In terms of the literacy levels, Indonesia has reached about 90% literacy for males and females (Statista, 2019). For the last two decades, women and men's participation in mandatory nine year education programmes (*wajib belajar Sembilan tahun)* in the New Order era (1966-1988) and mandatory twelve year education programmes (*wajib belajar dua belas tahun)* in the Reform era (1999 to the present) has resulted in around 90% school attendance for young Indonesians in 2016. Approximately 22% of male students and 25% of female students continued their study to university level the same year (Statistics of Indonesia, 2016). For example, in my study setting, in Palembang, the literacy level in Palembang is 98%, and the average length of education for those aged 25 or more, is ten years (Statistics of Palembang, 2018a). Yet other provinces and cities in East Indonesia, such as Papua have the lower percentage of literacy level compared to the national level due to disparities of education system and human resources in each province in Indonesia (Statistics of Indonesia, 2016).

Increased educational opportunities for both women and men in Indonesia contribute to more spaces for women to work in public spheres. Indonesian women, therefore, now have a greater chance of working outside the home to earn money without leaving their gendered family gender roles and have chance to be leaders in government institutions. The need for women in the working space increased in the beginning of the industrialisation era and public spheres the New Order (1966-1998) and the Reform era (1999-present day) (Prihatini, 2018b). Many factories were built and required workers and government institutions also required more staff, including women (Prihatini, 2018b).

In the leadership sphere, there has been a slightly increased opportunity for female leaders to take strategic positions in government, such as being (vice) president, (vice) governor, or other regional leadership role, particularly after the reform era (Dewi, 2015; Prihatini, 2018a, 2018b). At the national level, Indonesian experience was led by a female president, Megawati (2001-2004); out of seven presidents since the Indonesian's independence till now (2019). The current one, Indonesian has a female leader for House of Representative or *Dewan Perwakilan Rakyat* for 2019-2024, Puan Maharani, the daughter of Megawati Sukarno Putri (Ghaliya, 2019). At regional levels, in 2018 for example, 33% or 31 out of 94 female candidates who ran for local government offices were elected (governor, vice governor, regent and vice regent, mayor, and vice mayor (Prihatini, 2018b). Women's achievement in educational, economic, and political spheres, may influence their vulnerability to HIV transmission; this is discussed in Chapter 2.

This is important, as Indonesian women have moved progressively to actualise their ability in male and female spaces. Women's involvement in leadership has broken through the glass ceiling of dominant male leadership in current Indonesian politics. Ideally, having female leaders in the Government of Indonesia may open more opportunities for female leaders to accommodate family needs (UNWOMEN, 2019). However, gender norms within women's organisations and women's leadership in political sphere may impact on a woman's role, even after women choose to work outside of the home they will still continue to reinforce and maintain their gendered position in the family and subordination of men within patriarchal society. For example, even whilst in power, Indonesia's only female president, Megawati Sukarnoputri, said her chief occupation was still as *ibu rumah tangga*, serving her husband and children before anyone else in the nation (Najmah, Davies, & Andajani, 2020). In addition, women's capability for political leadership, however, may be overshadowed by the oligarchy and political kinship within a patriarchal society[3] (Dewi, 2017; Prihatini, 2018a).

This second-sub section provides an overview of the cultural norm, that the desire to get married and be a good mother and wife, is still strongly embedded within Indonesian women's everyday expectations, despite the increased women taking roles in the public spheres.

---

[3] In political spheres in Indonesia, some factors may contribute to their winning votes, including experience of being legislative members, women's religious identity, and previous experience as a leader or members in women's organisations and political parties (Dewi, 2017; Prihatini, 2018a). Women's capability for polical leadership, however, may be overshadowed by the oligarchy, including political kinship and capital in Indonesia. For instance, Megawati, a former female president of Indonesia, is a daugher of the first president of Indonesia, Soekarno and Megawati's daughter is elected as a leader for House of Representative (political kinship); and Khofifah Indar Parawansa, a current Governor of East Jawa, was a former leader of the female wing (Muslimat NU) of one of the biggest Muslim organisations, Nahdatul Ulama (oligarchy) (Dewi, 2017; Prihatini, 2018a).

Women's organisations and leadership positions in the public sphere are more evident, and impact on women's roles and opportunities. Improvement of maternal health is needed to protect women from preventable death during pregnancy and delivery, particularly for HIV-positive women.

Palembang (research area): Socio-demographic profile

Geographically, Palembang is bordered by the Banyuasin Regency on the north, east, and west, and Muara Enim and Ogan Ilir Regency in the south (Figure *1.5*). The area is about 40,061 km^2 with a total population of 1,580,517 in 2015 or around 3,000 inhabitants per 1km^2. Palembang is divided into two main areas by the Musi River: Seberang Ilir and Seberang Ulu. There are 18 districts (*kecamatan*) in Palembang with 107 subdistricts (*kelurahan*) in all *kecamatan.* The majority of Palembangnese are Muslims (92.82%). The life expectancy in Palembang is around 71 years on average.

Figure 1.5: Map of Palembang, South Sumatra

Note: Reprinted from *Palembang, Sumatra Selatan* by Google Maps, 2019. Copyright (2019) by Google Maps.

In terms of human development indices, the average annual income of a Palembang worker is about Rp 14,6 million (NZ$1600) or about Rp 1,2 million per month (NZ$130)[4]. Those living with low incomes (Rp 480,735 or NZ$45 monthly) are about 11.4% (184,000) of the total population (Statistics of Palembang, 2018). For government officials or PNS (*pegawai negri sipil*), the basic salary or regular pay (*gaji pokok*) is estimated as between NZ$200 and NZ$600 a month (GoI, 2015). Nevertheless, additional incentives such as performance allowances (*tunjangan kinerja*) can range from NZ$200 to over NZ$50,000 a month, depending on tenure and the position in the particular government institution (GoI, 2014).

Additionally, of 1,204,088 people in Palembang aged over 15,749,821 were categorised as '*angkatan kerja'* or employed in 2017 (Statistics of Palembang, 2018c). The number of women working at that time was approximately half of the number of men; that is, 272,791 women, compared to the 477,030 men working in 2017. Others were students or those undertaking unpaid domestic work in the home, and categorised as unemployed or *tidak bekerja*. Palembang has 468 elementary schools, 244 secondary schools, 139 senior high schools, and 79 vocational schools and both men and women over 15 years old have similar opportunities to access education (67,056 men versus 69,305 women) (Ministry of Education and Culture, 2018). While men and women over 15 years old have similar opportunities to access education (67,056 men versus 69,305 women), unpaid domestic work in the home is still largely undertaken by women, about 91.78 % (249, 938) compared to men 8.22 % (22, 381) (Statistics of Palembang, 2018c). Arguably, the statistics may not cover the real percentage of women in unpaid domestic work, as some may be categorised as *tidak bekerja,* though in reality they may earn money to support their families by working in the informal economy (for example-e.g.- cleaning, entrepreneurship or *wiraswasta*, and sex work), which does not get captured in the statistics.

Palembang: Health sector

Palembang has two public hospitals (Moh Hoesin and Bari Hospital), 33 private hospitals, 32 maternity hospitals/clinics, 41 *puskesmas* (public or community health centres), and 70 *puskesmas pembantu* (public health sub-centres) and *posyandu* (maternal and child centres) (Statistics of Palembang, 2018b). According to Palembang statistics, in 2017, the Palembang

---

[4] My experience indicates that in Palembang, a take-away lunch can be as low as NZ$1 -NZ$5 and public transport fares are as low as NZ$50 cents to NZ$2 for short distances.

Public Health Organisation employed hundreds of health workers: 781 specialists, 867 medical doctors, 370 midwives, 270 nurses, 177 dentists and over 500 other health workers (Statistics of Palembang, 2018b). The ratio of health workers to population is estimated about 0.5 per 1000 population or about 2000 health workers for 1, 2 million populations in Palembang.

In terms of ante-natal visits, the majority of pregnant women (about 90% of 29,610) in 2017 had made at least four visits. Contraceptive methods among married spouses still focussed on women's participation, and included progesterone injections, pills, and implants, while other methods were considered low (Intra Uterine Devices [IUDs] at seven percent, condoms at four percent, tubectomies at four percent, and vasectomies at three percent among 288,412 spouses accessing contraceptive methods in 2017) (Statistics of Palembang, 2018b). The trend of contraceptive methods is similar at national level, with majority user of contraceptive are women and low use of condom (only 7.5% of women use non hormonal methods, including condoms at about 4%) (MoH, 2013e; Praptoraharjo et al., 2016b). Low condom usage among married couples may be related to access and stigma related to condoms being associated with prostitution or sex outside marriage (Praptoraharjo et al., 2016b). There were high rates of some communicable diseases such as dengue haemorrhagic fever, tuberculosis, pneumonia, diarrhoea, and HIV [Palembang Public Health Office (PHO), 2018].

Palembang: HIV prevalence and programmes

Prevention of mother-to-child transmission of HIV is my research topic, and Palembang, the capital city of South Sumatra, was the field site of my research. Of the 1.6 million people in Palembang, approximately one in 300 are HIV positive (in epidemiological terms: HIV prevalence rate[5] about 0.33 %) (Palembang PHO, 2018). Over 22 years from 1995 to 2017, Palembang had the highest number of HIV and AIDS cases in South Sumatra (Figure *1.6*); estimated at 1,175 out of 1,565 HIV cases, and 1,119 out of 1,681 AIDS cases or about 70% of all HIV and AIDS cases in this province (South Sumatra PHO, 2018).

In terms of health services related to HIV, Palembang has STI Clinics, Voluntary Counselling and Testing (VCT) clinics, and hospital-based HIV care and PMTCT services. In 2017, antenatal HIV tests had been provided in all *puskesmas* in Palembang (see Table 1.2:; South

---

[5] 'HIV Prevalence rate' is the number of HIV cases as a percentage of the total population at risk, either during a period of time (period prevalence) or at a particular date in time (point prevalence).

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 2012-2017[6].

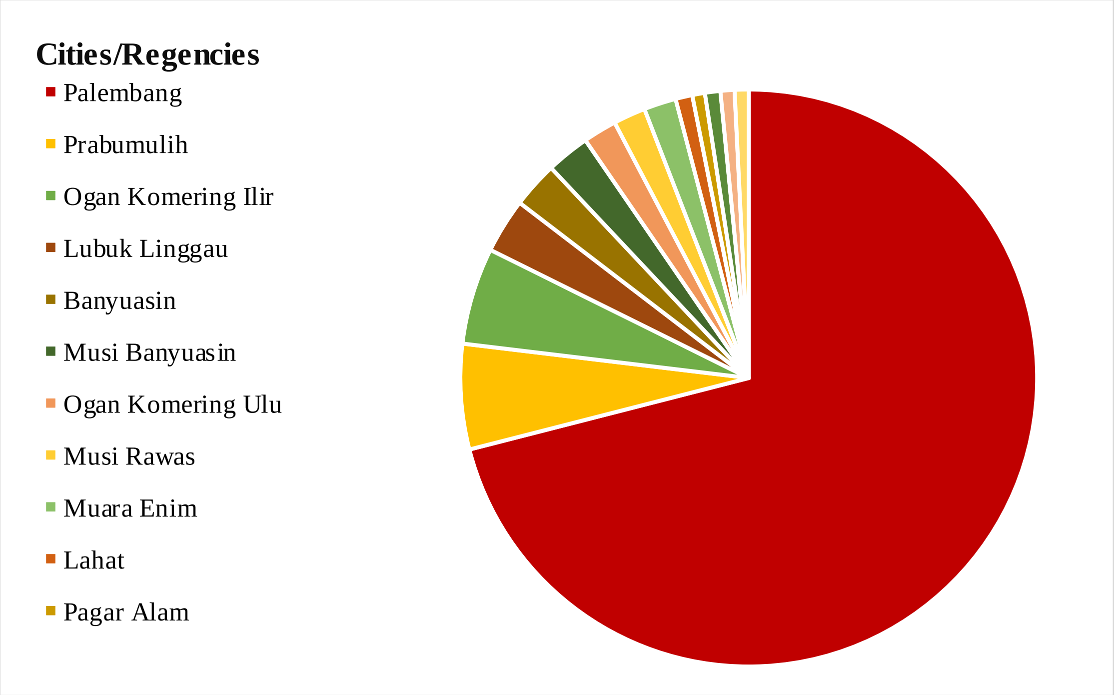


Figure 1.6: Cumulative number of HIV in 20 cities/regencies South Sumatra (1995- April 2017)

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.

Table 1.2: Health services related to HIV in Palembang

Types of Services related to HIV	Number of healthcare providers	Note
STI Clinics	4	Puskesmas: 23 Ilir, Dempo, Sukarame and Merdeka
VCT Clinics	13	Hospitals: Moh Hoesin; Charitas; Ernaldi Bahar; Myria, Muhamadiyah; Siti Khadijah; Siloam Sriwijaya; AK GANI Puskesmas: Dempo; Sukarami; Merdeka; Sukarame Prisons: Merah Mata and Female prisoners
New VCT Clinics*	12	Puskesmas 23 Ilir, Kertapati, 4 Ulu, Gandus, BoobBaru, Kenten, Puntikayu, SeiSelincah, Multiwahana, Semaatng Borang, Kalidoni
HIV Care, Support, and Treatment (CST)**+Tuberculosis HIV treatments	6	Hospitals: Moh Hoesin, Ernaldi Bahar, Charitas, Myria, Siloam Sriwijaya, Siti Khodijah Puskesmas: Dempo
PMTCT of HIV Services	2	Moh Hoesin Hospital and Charitas Hospital
Antenatal HIV screening***	41	All puskesmas

Sources: South Sumatra PHO, 2017, Palembang PHO, 2018 and managers of HIV in South Sumatra PHO and Palembang PHO, personal communication, 2017

Note:

** 12 new VCT centres were setting up at the end of 2017 to support HIV-TB programmes and PMTCT services;*
*** Care, Support and Treatment or CST, Indonesian literally PDP or Perawatan, Dukungan, dan Pengobatan;*
**** Implementation started on 2017 in all puskesmas.*

8. My position as a researcher

This section examines my position in the research. As a novice Feminist-Participatory Action Research researcher, I realised positionality was an integral part of this study. According to Merriam et al. (2001), positionality is “determined by where one stands in relation to ‘the other’, and more importantly, these positions can shift” (p. 411). Banks (1998) added that a personal interpretation is informed by the interaction of a complex set of factors including the region, age, class, gender, religion, and political status of the researcher. My multiple insider and outsider positionalities impacted on knowledge production and representation during the research process and analysis. Therefore, I was aware of my own privilege, as well as my unprivileged background in relation to HIV-positive women and other complex power dynamics (see Merriam et al., 2001). I start with the reflection on my position as an insider.

Being an insider

Having the same sex, religion, status as a mother, nationality, and culture as participants, allowed me special privilege to access certain knowledge, perspectives, and experiences of HIV-positive women (See Banks, 1998; Merton, 1972). I was born, lived, and work in Palembang. As a Palembang Muslim woman, living primarily in Indonesia, I have been taught to be devoted to Islam, get married, and be a faithful wife, as a part of my religious and social upbringing. As an Indonesian woman, I was raised to value marriage as a sacred bond (*ikatan suci*), a source of pride and a dream. These values I shared with many of the HIV-positive women in this study who also desired to be married to a responsible husband, and have children of their own. My role in society and in my family also involved marriage, having children, and jointly raising them with my husband, sharing our family responsibilities (see Chapter 2, Expectations of women in Indonesia).

My parents and relatives trained me to be aware of the special position my husband has as the head of the family within our religion and culture; as a wife, I was expected to obey him and gain his consent for all decisions. Therefore, I should not ask my husband about his past, his sexual experiences, or enquire about possibly disloyal behaviour. Any enquiries or suspicions from me, as his wife, would be seen as disobedience to my husband. As a mother of two girls and one boy, born in 2013, 2015, and 2017, I empathised with all of the women in my study, and the responsibilities that a mother has in raising her children, and making sure they are healthy and well looked after. I know how horrifying it is to have a sick child, let alone having one who is HIV-positive. Being a mother who was also pregnant during my fieldwork, may have contributed to gaining their trust in my role as a mother in Indonesian society.

The study participants, nevertheless, wanted to present themselves as responsible women, or good women (*perempuan baik-baik*) and they would probably have worried that I may have been judgemental in spite of my expressing a lack of judgement. Thus, being an insider both helped and hindered me. I learnt how building trust contributed to the authenticity of my participants' voices, particularly in relation to sharing experiences of their private lives, such as the experience of being a sex worker, a female IDU, and the second wife of their current husband, all of which are taboo topics in women's lives.

By the time I conducted this research, I had had two caesarean sections. These experiences gave me insights into what most of the participants had undergone, or were about to undergo, a caesarean delivery is a default option to prevent HIV transmission to babies. I recalled the stiffness I felt and the pain in my body the day after the operation, and while walking during the first two weeks postpartum. I understood that good support from a husband and health workers was important before, during, and after any caesarean delivery. I shared this experience with participants who had undergone caesarean operations.

Being an outsider

I was fully aware that I was not a part of my participants' HIV-positive women community. I came from a different socioeconomic background, as I have a higher education qualification obtained overseas. I had the privilege of not worrying about the cost of accessing health services and I could freely move to other social groups without fear of stigmatisation. I learned from my participants that there is stigma against women living with HIV, as they are thought to be promiscuous (*perempuan nakal*) and unfaithful wives. I also realised that, accessing HIV treatment and services meant they were required to disclose their HIV status and face stigmatisation from their families, communities, and some health workers, due to the lack of confidentiality in health settings.

The challenge of being an outsider amongst this vulnerable group of HIV-positive women was overcome by gaining access to my population of interest, building trust, and respecting confidentiality (see Merriam et al., 2011). I anticipated that it would be extremely hard for these women to disclose their HIV status. Therefore, I conducted informal information sessions with individuals and groups before any data were collected. By knowing them better, mingling, sharing stories and food, hugging, shaking hands, and visiting their houses, I challenged my own fear of being infected with HIV, and in return, I gained their trust.

I was an outsider to the participants who were single parents, either widows or divorcees. Being a divorcee is taboo, and these women are considered as failures and are stigmatised; the stigma even extends to widows who have become single, against their will and power to prevent it. Divorcees and widows (*janda*) are considered a threat to other wives in Indonesian society due to a belief they are sexually available and promiscuous (Parker & Creese, 2016; Parker, Riyani, & Nolan, 2015). I learned that most of the women discovered their HIV status in the late stages of their HIV infection, and only after their husbands' or children's sickness or death. As noted earlier, it is still widely considered inappropriate for a wife to ask about her husband's past, 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 methodology to create a safe collective space for marginalised women. I expand on these on Chapter 8 and 9.

The evidence from this study suggests the importance of positioning HIV-positive women as a central focus of the study and as the real knowers of their problem and experts in relation to solutions to their problem. The 18 HIV-positive women involved in this Ph.D. study felt empowered and confident to propose solutions to problems. They addressed the obstacles of structural inequality and gender relations that situated them in a place of inferiority. Their voices and concerns have been ignored and dismissed by the PMTCT services. By inviting women as the experts in their life experiences to be creative agents of change, results from this study provide insights into women's involvement as change agents in PMTCT services, both in the Indonesian context and in other countries of similar context. Solutions that come from HIV-positive women themselves will be relevant to the lives of other WLWH, who also experience stigmatisation and discrimination. Therefore, this research provides a case study for predominantly Muslim communities of other developing nations where there are many factors at play, including ideological, cultural, and religious influences. My findings suggest that it is necessary to create a space for women to be empowered and listened to and for health workers to understand the complexity of women's lives when trying to access PMTCT services.

Finally, it is hoped that this study will be the beginning of ongoing research into women's participation in HIV programmes and policy development globally, by addressing the multi-layered, complex socio-cultural and political context of women's lives, particularly marginalised women, such as those who are HIV positive, a wife, and/or a mother. Next, I close this introduction chapter by outlining the structure of my thesis.

10.Structure of the thesis

This thesis is structured into nine chapters.

Introduction (Chapter 1)

In this chapter, I introduced the purpose of my study, positioned myself as the researcher, identified the research gaps and the significance of the study, and outlined the thesis structure. I explore the earlier research on HIV among *ibu rumah tangga* in Indonesia and then discuss what I offer in this participatory action research.

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'.

Chapter 5 examines in detail who the participants were and how their positioning and experiences their vulnerability. The three cases of HIV-positive women analysed astutely to show key patterns of vulnerability as well as the complexity and diversity of women's experiences.

Chapter 6 analyses barriers affecting women's access to appropriate care focused in three parts on access to testing, experiences after diagnosis, and discrimination in access to PMTCT. This chapter integrates the women's experiences to accessing PMTCT services and voices and varied perspectives of health workers. It demonstrates how the roles and practices of health workers are pivotal in determining women's access to and experiences with health care and analyses how unequal gender relations in marriage shapes women's ability access care.

Chapter 7, the third of three chapters that present and analysed field data, provide the four interrelated spheres of the individual, the family, health workers and the Government of Indonesia to enable women to access PMTCT services. The chapter analyses diversity of voices through visual and creative outcomes created by HIV-positive women and their family, NGO workers, and health workers, including songs, poems, drawings, role-play and mind-mapping. It concludes the importance of both HIV-positive women and health care workers as key informants and experts on solutions to addressing accessing to PMTCT services for developing relevant and realistic strategies to address barriers from both the demand and supply sides of the health system in Indonesia.

Discussion (Chapter 8)

Chapter 8 articulates the three concepts have made original contribution to several areas of scholarship the theoretical contribution of public health work on HIV in Indonesia and Indonesian sexualities studies. First, I introduce the concept of 'marital deception'. The perception of a monogamous marriage providing protection and safety family is prevalent, however, the marital deception may increase women's risk to get infected to HIV. Second, I outline the concept of intersectionlality and women's vulnerability to HIV. Women are vulnerable to HIV transmission, regardless of women's socio-economic status; however, some women may deal with intersection of different elements to disempower or empower them to access PMTCT services. Third, I discuss the concept of HIV-related stigma or shame. It happens in different ways of different groups of HIV-positive women and health workers. This chapter provides a clear explanation of a silent epidemic threat in Indonesia with a concentrated HIV epidemic country in a low-level epidemic setting.

Translating Research Knowledge into Practice (Chapter 9)

In this chapter, I discuss the translation of research findings into action and recommendations for policy/programme makers on PMTCT services and research with HIV positive women. I analyse details messages of the actions related to four-pronged strategy of PMTCT programme stemming from the implementation of the FPAR Methodology. The contribution of an example of to effectively implement the FPAR framework in the Indonesian context and in relation to a highly marginalised group of women demonstrates a template for and the utility of this approach in this particular cultural and religious setting.

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

1. Introduction

Chapter 1 provided an overview of my research topic and the significance of my research. It showed a need for early diagnosis of HIV among mothers and wives to prevent HIV mother-to-child transmission and the urgency of enabling HIV-positive pregnant women to access health services. Yet, because of the multiple barriers to accessing Prevention of Mother-to-Child of Transmission (PMTCT) services, as discussed in Chapter 3, *ibu rumah tangga* may transmit HIV to their babies with or without being aware of their own HIV status. This chapter, Chapter 2, presents literature and discussion on the context of the HIV vulnerability of women.

The chapter overviews factors likely to influence women's vulnerability to HIV, particularly Indonesian women. Notably, the discussion focuses on heterosexually married women within Muslim communities. The chapter is divided into three main sections: 1) the vulnerability of women; 2) the societal expectations of women in Indonesia; and 3) the societal reality for women in Indonesia: why women are vulnerable to HIV in Indonesia.

I start with a quick overview of the vulnerability of heterosexually (married) women globally, followed by an explanation of why we need to understand women's expectations in Indonesia before discussing women's HIV vulnerability in an Indonesian context. The second section focuses on Indonesian women's status within the national development agenda and the dominant interpretation of religious teachings that are embedded across interpersonal/kinship systems, as well as in social and public policy spheres. The third section summarises the intersection of the different factors of women's expectations discussed in the second section, that may be associated with their HIV vulnerability. This chapter illustrates how the intersectionality lens is important for gaining an in-depth understanding of the complexities of women's social positions, roles, and the wider social gender norms relating to women's vulnerability to HIV in Indonesia. According to Bowleg, understanding women's health requires consideration of the intersectional influences of "social-structural factors beyond the level of the individual", that influence women's vulnerability to HIV (2012, p. 1269). This chapter, therefore, focuses on the socio-cultural factors that play a bigger role in women's vulnerability to HIV.

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 physiology[7] 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.

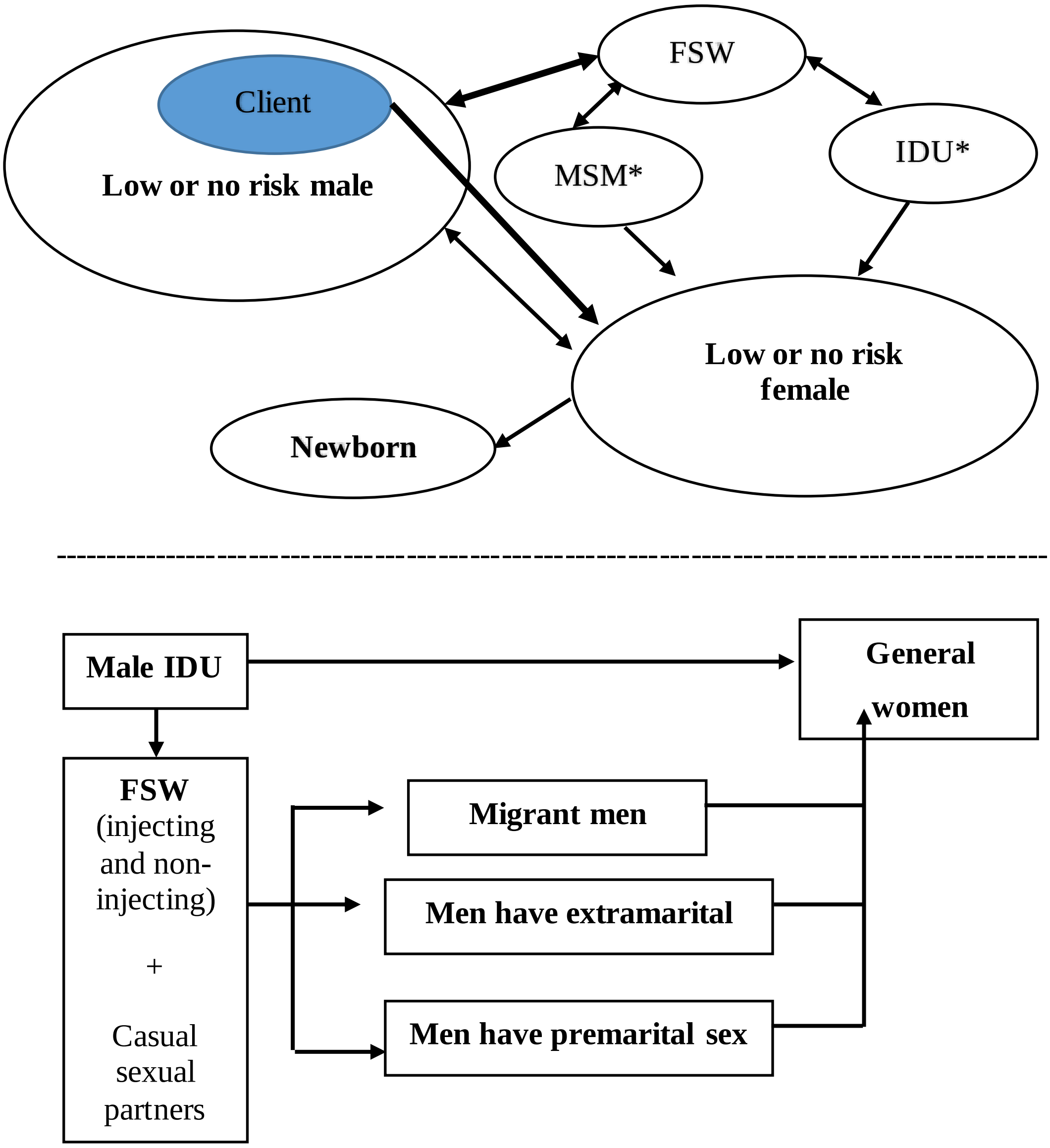


Figure 2.1: Possible routes for transmission of HIV to women in the wider population in Thailand (picture 1) and Vietnam (picture 2)

Note. FSW: Female Sex Worker, MSM: Men having sex with men, and IDU: Injecting Drug Users. Reprinted from 1) Picture 1: elimination of mother-to-child transmission of HIV: lessons learned from success in Thailand by Thisyakorn, 2017. Copyright (2017) by Thisyakorn; and 2) Picture 2: a hidden HIV epidemic among women in Vietnam by Nguyen, Oosterhoff, Hardon, et al., 2008. Copyright (2008) by Nguyen, Oosterhoff, Hardon, et al.

The Figure 2.1 illustrating the dynamics of HIV transmission in Asian countries (such as Thailand and Vietnam) highlight the increasing number of HIV infections among heterosexual married women and men through unsafe sexual practices, as condom use is still not common in the Asian context. Arguably, these studies tend to decriminalise IDUs, MSM, transgender people, and female sex workers, who are viewed as anti-social or immoral. The decriminalisation of such groups can reduce *ibu rumah tangga's* awareness of their own HIV status. Additionally, in the South-East Asian context, the mobility and HIV vulnerability of men and women engaged with transient and tourist populations may contribute to engagement in unsafe sexual practices (e.g. extramarital affairs or accessing to sex workers). Nevertheless, these mobile groups may have steady partners, wives or husbands with whom they also engage sexually [see Skeldon (2000)].

Other contributing socio-cultural factors, such as women's personal belief that they are at low risk because they are married, their lack of knowledge, societal negative attitudes towards to HIV, laws which discriminate against women (e.g. in relation to inheritances and marriage), inadequate education for women, and women's economic dependence on their husbands, may all exacerbate women's vulnerability to HIV, as found with Chinese and African American women (Lin, 2007; Brawner, 2014). Consequently, men with HIV increase women's vulnerability if the men are silent about their HIV status, so the women may not know they are at risk due to gender inequality (Higgins et al., 2010; Lin et al., 2007).

Female reproductive systems

Women's reproductive systems may also exacerbate women's vulnerability to HIV, as the second contributing factor to increasing women's vulnerability to HIV. Women's reproductive organs differ physiologically from those of men, including the shape and anatomy of the genital tract, and the culture, moisture, and internal environment of their reproductive organs (Drake, Wagner, Richardson, & John-Stewart, 2014; Higgins et al., 2010; Ostrach & Singer, 2012; Thorne, 2014). Thus, women's reproductive organs are fragile and susceptible to damage[8] when a woman is pregnant, using a hormonal contraceptive and an intra-uterine device (IUD), enhancing the risk of infections of the cervix and risk of HIV if their partners are HIV-positive (Higgins et al., 2010; Lin et al., 2007; Morrison et al., 2007; Ostrach & Singer, 2012).

---

[8] When a woman is pregnant or using hormonal contraception, her cervical ectopy (cervical erosion) or the soft cells lining the inside of the cervical canal, extends outwards on to the vaginal portion of the cervix (Drake et al., 2014; Ostrach & Singer, 2012; Thorne, 2014). In addition, using an intra-uterine device (IUD) as a contraceptive method, increases the risk of vaginal bleeding (Ostrach & Singer, 2012).

Global studies argue that a woman's vulnerability to HIV is not only influenced by her physiological factors, especially her reproductive organs, but her socio-cultural life circumstances also play a bigger role in her vulnerability (Baral et al., 2013; Brawner, 2014; Higgins et al., 2010; Lin et al., 2007; Ostrach & Singer, 2012). These socio-cultural factors and other contributing factors are interlinked with different domains of women's lives, such as their personal circumstances, married lives, social environment, and factors relating to public policy. Thus, there is a need to examine the country-specific socio-cultural and religious context to understand women's vulnerability to HIV, in order to create better HIV prevention for women (Brawner, 2014; Lin, 2007).

3. Expectations of women in Indonesia

Before explaining women's vulnerability in the specific context of Indonesia, it is important to understand women's expectations in Indonesian society. I reflected on my own journey below to introduce the dominant societal expectation of having a family in Indonesia. The desire to get married, and be a mother and wife, is strongly embedded in Indonesian women's everyday lives. As an Indonesian woman, I am often asked questions in relation to my role as an Indonesian woman.

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

This section describes Indonesian women and two particular aspects of Indonesia which shape women's lives: 1) Indonesian women and government policies, and 2) Indonesian women and Islamic values, which are patriarchal. I specifically focus on Islam, based on my participants' and my own religion. I present evidence that elements of marriage, childbearing, and childrearing are embedded in Islam, and reinforced politically, culturally, and socially in Indonesian women's daily lives. Status and values within Indonesia differ considerably for men and women, and dominant patriarchal norms may impact on women's increased vulnerability to contracting HIV. For note, the differences do exist between women of different classes, and for women of different ethnic groups and women who practice different types of

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 wrote about the cultural norms of marriage and motherhood for female Sumatrans, followed by research in the 20th century by Djajadiningrat-Nieuwenhuis (1987), who coined the term *Ibuism*[9] and by Julia Suryakusuma (1999) who coined the term State *Ibusim* to indicate the strong value of motherhood for Indonesian women. Gender ideology also impacts on role differentiation between men and women in Indonesia in the past and present (Locher-Scholten & Niehof, 1987). I specifically focus on the era after Indonesian's independence.

After independence from the Dutch in 1945[10], the notion of a nuclear family was promoted widely in Indonesia (as it was in other Asian regions), as a part of the nation's development, particularly under the first and second presidents, Soekarno and Suharto (Platt, Davies & Bennett, 2018). As noted previously, state *ibuism* was a particularly critical ideology that manifested in the New Order policies and government institutions. Suryakusuma's work published in 1999, argued that gender ideologies were manifested in national agendas and nation-wide institutions, such as *Dharma Wanita* (Indonesian literally the five duties of women) and PKK or *Pemberdayaan Kesejahteraan Keluarga* (Family Welfare Movement).

The term "*dharma"* in this context, refers to a woman's five duties: being a faithful wife, having a role as a mother caring for her children, managing a household, being a supporter of her husband (such as working outside home to help with finances), and being an Indonesian citizen[11] (Pertiwi & Yulindrasari, 2018; Suryakusuma, 1999). Women's organisations, while at times advocating for women's welfare and wider public participation, reinforce restrictive

---

[9] Some examples of gender ideology before Indonesian independence are: "1) Man has a significant role in the initial phase of procreation and production; women as mothers (*ibu*) have the significant but secondary role of looking after, caring and educating children; 2) Women are positioned as brides and good wives and sacrificing mothers, but with no power in family decisions; young girls are to be brought up as sweet, modest, obedient, and diligent. A good wife should accommodate male sexuality, confirm herself as *darat* (or at home or in the village) and support her husband; and 3) Rahman El Yunisiya, daughter of an influential member of the *ulema* (Islamic scholars), became an important political figure among Muslim reformists due to her contribution to the formation of *Kaum Mudo*, a group of energetic and educated women, which played an important role in the nationalist movement [read Locher-Scholten and Niehof (1987), cited by Narli (1989, pp. 111-114)]

[10] Indonesia became independent on 17th of August 1945. However, after this announcement of independence, there was an effort at decolonisation of Indonesia by Dutch and other West countries (*negara sekutu).* Additionally, Indonesia, in the first decade of independence, still dealt with many internal conflicts among different regions, ethnicities, and political parties (Ricklefs, 2008)

[11] Indonesian literally 1) *istri pendamping setia suami; Ibu pendidik anak dan pembina generasi muda penerus bangsa*; 3) *pengatur rumah tangga*; 4) *sebagai pekerja penambah penghasilan keluarga; dan* 5) *anggota masyarakat yang berguna*.

understandings of these roles of women, and risk limiting the empowerment of women to make decisions that ensure their rights to equality (Pertiwi & Yulindrasari, 2018; Suryakusuma, 1999). Nevertheless, the social hierarchy in Indonesia is based on the power and authority of male partners or husbands working for the Government of Indonesia,[12] and female leaders cannot exert any authority over their male partners in government institutions.

The Government of Indonesia also manifested societal expectations of husbands and wives by passing regulations to protect women's and children's rights by registering their parents' marriages in religious departments in each province. Before 1970, there was no specific regulation considering women's rights in a formal marriage institution. Therefore, unilateral divorce could take place without the knowledge of, or consultation with the wife, as well as arbitrary polygamy (when a man marries another woman without the knowledge of his first wife), and de facto divorce (in which a man does not divorce his first wife, but neglects this wife and their children). This is also referred to as the 'abandonment of women and children by their husbands' (Nurmila, 2009, 2016). Therefore, the government regulated registered or lawful monogamous marriages, restricted polygamy, and banned extramarital relationships (in the Constitution of the Republic of Indonesia in 1945 [UUD (*Undang-Undang Dasar*) 1945], Indonesian Marriage Law no 1 in 1974, and government regulation (*peraturan pemerintah* or PP) no 45 in 1990[13]). This is discussed in the second sub-section.

In summary, societal expectations of women intersect with government policies and institutions in Indonesia. State *ibuism* can be considered as gendered ideology in contemporary Indonesia. Hence, for many decades, a gendered ideology has been embedded in and penetrating Indonesian social structures, endorsing the hegemony of family and marriage life. This may create problems even for those women who fall outside the patriarchal hegemony. Examples of this "outsider" status would be sexually-active single women, pregnant unmarried

---

[12] Leadership of PKK and Dharma Wanita is determined by the woman's husband's position in his community or state organisation. That is, both organisations reflect the state's hierarchical system; the head of the organisation is the wife of the highest ranking officer in the local or central government system or village governance (Campbell, 2007; Candraningrum, 2015; Sears, 1999; Suryakusuma, 1999).

[13] UUD 1945 were passed under the leadership of Soekarno (The first president of Indonesia) during the Old Order (*Orde Lama*) and the marriage regulations were passed under the leadership of Suharto (the second president of Indonesia) during the New Order

women, female divorcees and widows, and single or unmarried women[14]. 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 husband[16] (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

health services, and public insurance), inherited laws; divorce polygamous marriage (see Platt, 2017, Nurmila, 2009).

Restricting polygamous marriages and divorces

In this third sub-section on Indonesian women and government regulations, I explain polygamous marriages and divorce in Indonesian legal systems (the Indonesian Marriage Laws no 1 in 1974 and PP No 45 in 1990). The practices of polygamy and divorce, nevertheless, have been restricted and discouraged by the state marriage laws. For example, a husband who intends to practice polygamy must seek permission from existing wives and demonstrate to the religious court that he can fulfil specific criteria. These include evidence of his wife's infertility, incurable sickness, or disobedience, and that he is able to financially support another family fairly[17]. Divorce has to take place in the Religious Affairs Court[18], followed by an attempt at reconciliation before the final decision is made[19] (Indonesian Ministry of Religious Affairs, 1991).

PNS or public or civil servant men in government institutions who want to propose polygamy or divorce their wives, must request permission from the leaders in their institution by writing a formal letter[20] (GoI, 1990). State workers are also not allowed to undertake unregistered or extramarital relationships or practice infidelity (*selingkuh*)[21]. Sanctions, such as losing their jobs, exist to restrict the practice of polygamy, divorce, unregistered marriages and illicit relationships (GoI, 1990). Arguably, procedures in relation to polygamy and divorce, may contribute to the practice of unregistered marriages, secret marriages (*nikah diam-diam*), and hidden extramarital marriages (*perselingkuhan diam-diam*).

---

[17] See article 4 in the Indonesian Marriage Law no 1 in 1974

[18] A husband must say 'I divorce my wife' in front of the court for Muslim citizens

[19] See article 39, 40 in the Indonesian Marriage Law no 1 in 1974

[20] See article 3 and 4 PP No 45 in 1990

[21] See article 14 in PP No 45 in 1990

Consequently, within the hegemony of monogamous marriage as an ideal marriage, some practitioners of unregistered polygamous marriages[22] may have hidden these from other wives or excluded other wives' (lack of) consent (Mulia, 2009; Nurmila, 2009; Nurmila & Bennett, 2015). The practice of unregistered marriages, however, is widespread and growing in all parts of Indonesia, such as in the Javanese islands, and Western Nusa Tenggara (Lombok) (Nurmila, 2009; Platt, 2017). Therefore, the practice of polygamous marriage is sensitive and unregistered marriage has become a vehicle for secretive polygamous marriage. Without protection from the state marriage-based law[23], men can easily practise abandonment, unilateral divorce, and arbitrary polygamy in Indonesia (Nurmila, 2009, 2016; Platt, 2017).

Regulating the roles of wives and husbands but providing opportunities for women in the public sphere

This third sub-section of Indonesian women and government policies discusses the construction of women's positions in relation to the 1974 Indonesian Marriage Law and GBHN. The Indonesian government set out the wives' and husbands' roles and responsibilities, promoting equal rights for married people (such as parents are obliged to rear and educate their children[24]) but separate roles for wives and husbands in the domestic and public spheres, which may risk discriminatory practices. For example, women's domestic roles are emphasised, particularly their primary roles as housewives (article 31, section 3) and household managers (article 34, section 2), before their roles and participation in the public domain (GoI, 1974).

The Dharma Wanita and the PKK, as discussed previously, is still in existence. PKK is a movement at the community level, and the *Dharma Wanita* is an organisation for the wives of public servants (Robinson, 2000; Suryakusuma, 1999, 2011). Arguably, these women's

---

[22] There are no current statistics on polygamous marriage in Indonesia. However, in a survey in 1970, about two percent of Indonesian men practised polygamy (Nurmila, 2016)

[23] There were efforts to reform KHI by Muslim feminists who were rewriting "the Islamic Law on marriage based on gender-sensitive perspective" (White & Anshor, 2008, p. 146). The proposed regulation named "The Counter Legal Draft" promotes gender equality and empowers women, through rights to equal roles in managing households between husband and wife, registering marriage as one of the principles of *nikah* (marriage), and eliminating polygamy (Mulia & Cammack, 2007). Nevertheless, after public hearings of the draft, it was withdrawn by the Indonesian Ministry of Religious Affair due to conservative and fundamentalist views such as disagreement over banning polygamy, and disagreement over interfaith marriage (Mutaqin, 2018; White & Anshor, 2008).

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

organisations may provide women the opportunity to actualise their leadership within a women-centric space, such as a political sphere (Dewi, 2015), without leaving their *kodrat* (appropriate)[25] or natural roles as wives and mothers.

Increased educational opportunities for both women and men in Indonesia contribute to more spaces for women to work in public spheres (see Indonesia: Snapshots of Indonesian women's status and expectations in Chapter 1). The need for women in the working space increased in the beginning of the industrialisation era in the New Order and Reform era in the 19th century (Prihatini, 2018b). Many factories were built and required workers, including women (Prihatini, 2018b). Additionally, for the last two decades, women and men's participation in education resulted in around 90% school attendance for young Indonesians in 2016. Indonesian women, therefore, now have a greater chance than before of working outside the home to earn money while still maintaining their gendered family roles [see Andajani, Hadiwirawan, and Sokang, 2016, Damar, 2014 Nurmila, 2016].

Married women's roles now expand beyond the household (as mothers and husband supporters), to opportunities to work outside home and advance their education (Damar, 2014; Nurmila, 2016). Therefore, childrearing and household duties may be undertaken by women paid as house cleaners or child-minders for couples with the capacity to pay for these services (Damar, 2014; Nurmila, 2016; Suryakusuma, 2011). Alternatively, grandparents often help by caring for children whose mothers are working; however, that may double the burden of being a working mother and extend the burden to the parents of the working mother, such as in my own and female colleagues' experience. Nevertheless, it is not uncommon to hear career women in Indonesia saying that their primary commitment is always to their husband and children, before work or study, which may result in conflicting priorities and confusion [see Andajani, et.al. (2016); Nurmila (2016)]. Arguably, gender specific societal expectations of women and men may impact on the prevalence of women (more than for men) in unpaid domestic roles in the home, despite the increase in equal opportunities for education and for work outside home (UNWOMEN, 2019).

---

[25] "Kodrat" derives from the Arabic word "*qudrah*" which means "the ability to do a particular thing within the bounds of appropriateness" (Dewi, 2017, p. 118)

In summary, the desire to get married and be a good mother and wife, is still strongly embedded in Indonesian women's everyday expectations. Gender norms within women's organisations, women's working places, and women's leadership in the public sphere still continue to reinforce and maintain women's gendered positions in the family. I argue that being a mother and a wife still cannot be separated from women's roles in the dominant patriarchal Indonesian society, as women continue to carry the burden of combining domestic duties with public sphere roles. However, childbearing and childrearing are constructed by Indonesian society as a *kodrat* as well as are interpreted as worship of God in Muslim religious teachings.

Indonesian women and Islamic values

> As a Muslim woman in Sumatra of my generation (born after 1980), I was responsible for choosing a good man as a husband. I was raised with the value of having no sexual pleasure or sexual engagement before marriage. After getting married, I hoped my married life would be good, as well as my career, education, family, and religion. I was taught that marriage and motherhood was a part of worship of God (*ibadah)* and I learned to be sincere (*ikhlas)* in performing my motherhood roles for the sake of God, and to apply kindness (*kebaikan)* within my family. I also maintained my dignity as a faithful wife, and my husband's role to provide virtuous guidance and be the breadwinner of my family while sharing the roles of nurturing our three children (Najmah's Research Journal, 2018)

Having discussed how women's roles and expectations are constructed and reinforced by government regulations, next I explain how Muslim women are constructed by Islam. This section provides the dominant interpretations of marriage and religious expectations of women based on the holy book for Muslims, the *Al-Quran* or Quran and Hadith, which provides guidance to the daily practices of Islam as set out by the prophet Muhammad[26]. I divide this sub-section into three main parts: 1) defining heterosexual gender morality in Islam: historical context; 2) promoting monogamous marriage with restricted polygamy and divorce, and 3) being a good wife and mother.

Defining heterosexual gender morality: historical context

In this first sub-section on Indonesian women and Islamic values, I overview the historical context of Islam in Indonesia and how Islamic values are assimilated into social norms,

---

[26] According to the Islamic tradition, in 610AD Mohammad began to receive a series of revelations from God. He heard a voice commanding him to recite verses "In the name of Your Lord!" and over the coming years, he received a series of recitations that were first written down a few decades later in the text known as the Koran or Al-Qur'an." (Frankopan, p. 35)

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 centuries[27] (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 centuries [28]. 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 Mecca[1] (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).

Islamic teachings are now entrenched and dictate how people see themselves and identify with one another. Islamic values have been passed through Islamic teaching in public schools, Islamic boarding schools (*pesantren*), holistic Islamic schools (*sekolah Islam terpadu*), Islamic preaching, Islamic gatherings, word of mouth, and other social norms and social media (Formen & Nuttall, 2014; Kuntowijoyo, 2001; Martin-Anatias, 2018b; Nisa, 2018; Ricklefs, 2008). Arguably, Islamic norms are embedded in the religious expectations of good Muslim women, like other religious values which also construct Indonesian women[29], although Indonesia has not incorporated Sharia law (Islamic law) in its legal systems and regulations, except in Aceh (Davies, 2019; Heryanto, 2014).

Religious expectations on Muslim women around marriage and motherhood are defined by morality and gender morality, and the dominant interpretations of Islamic teachings are embedded in the common perspectives of Muslim mothers and wives. In past centuries, William Marsden observed the introduction of heterosexual monogamous marriages, as well as arranged, and polygamous marriages, which were also observed in Sumatra: Lampung, South Sumatra (Jambi), Bengkulu and Riau (Marsden, 1788). Those who fall outside the practice of heterosexual morality, would be seen as 'other' and may lose face or be made to feel ashamed or ostracised as outsiders. Outsiders who have extramarital affairs face social punishment (*adat punishmeht).* In Marsden's time in 1970s, such punishments may have required them to pay a lump sum, sacrifice buffalo and a hundred bamboos of rice, become a slave or even be required to leave their village, to be isolated from their community (*bersih desa)* (Marsden, 1788).

Such social penalties are still embedded in contemporary Indonesian thinking, but with a different approach. Sex outside marriage or premarital sex and pregnancy outside marriage are socially condemned and place women as objects of gossip; such women are considered immoral (Bennett, 2005; Davies, 2015; Nurmila, 2016) and risk bad luck to their family

---

[29] Generally, the majority of religious teachings, such as Christianity, Buddhism, Hinduism and Confucianism, endorse an aspiration for the creation of a harmonious marriage; a wife is partner to her husband in a monogamous heterosexual marriage, a husband provides virtuous guidance for his wife, and divorce is either not allowed or restricted (personal communication with Indonesian non-Muslim friends, 2019). Another example is found in Thailand, where the majority of Buddhist, Isan women are constructed as being a good wife, mother, and daughter-in-law and faithful to her husband, as well as maintaining the health and well-being of her family (see Andajani, Chirawatkul, &Saito, 2015; Chanthasukh, 2019).

(Blackburn et al., 2008). The current initiatives to review the Penal Law abolishing sexual assault or *Rancangan Undang-Undang Penghapusan Kekerasan Seksual* in Indonesia include criminalising consented sexual relationships outside marriage and criminalising abortion and regulating penalties for sexual intercourse without mutual agreement in a marriage to protect women from sexual harassment. This review has been put on hold by the current President Joko Widodo (GoI, n.d.). This current initiatives aim to protect women's sexual and reproductive right as well as maintain the hegemony of registered marriage in Indonesia.

Within the hegemony of an ideal family of a husband and a wife with at least two children (boy and girl), if the woman becomes a divorcee or a widow, she risks social stigmatisation on top of the burden of her dual roles as single parent and income earner for her family. The studies of Parker and Creese (2016); Parker, Riyani, and Nolan (2015) noted that "divorcees typically experience more shame and more sexual innuendo than widows" (Parker et al., 2015, p. 42). See for example, in Chapter 5, the story of Mawar, a young attractive divorcee who decided to leave her hometown due to the shame she brought to her family and the story of Oneng, who reunited with her husband, who had had extramarital affairs and used illicit drugs during their two-year separation.

As noted earlier, it is impossible to absolutely disentangle the influence of patriarchal values from heterosexual gender morality which penetrate many different aspects of women's life in Indonesia or distinguish them from religious norms, as they reinforce each other. The following section considers the dominant interpretations of Islamic teaching that construct the expectations of Muslim women in Indonesia.

Promoting monogamous marriage and restricting polygamy and divorce

Islam informs every aspect of a woman's sexual life, including motherhood and sexual pleasure, but these aspects mostly occur within the parameters of the assumption of heterosexual marriage. As a married woman in Islam, I was raised with values of marriage in Islamic teachings, to provide a stable and righteous environment for a woman and a man to express their natural biological, physical and emotional needs, to produce and raise children, and provide a legal union within family and society.

Islamic marriage covers both aspects, *ibadah* or worship of Allah (God) and *mu'amalah* (transaction between human beings) (Isgandarova, 2016; Pappano & Olwan, 2016). Marriage is considered as completion of half of one's faith[30]; it is a lawful and virtuous institution responding to the basic biological instincts of human beings, to express sexual pleasure or desire, to bear children (*keturunan),* to fulfil one's tranquillity (*Sakoon*, in Arabic), affection (*Mawaddah*, in Arabic), and mercy (*Rahmah*, in Arabic) in a human life (Ebrahim, 2007; Ibrahim & Songwathana, 2010). In Indonesia, these Arabic words are expressed as *Keluarga sakinah, mawaddah and warohmah*, and are often used to congratulate a newly married person.

The Compilation of Islamic Law (*KHI, Kompilasi Hukum Islam*)[31] was based on President Instruction (*Inpres*) no 1 in 1991 to support the Indonesian Marriage Law for Indonesian Muslims (Indonesian Ministry of Religious Affairs, 1991; White & Anshor, 2008). The first is for a woman and a man to commit to a marriage bond or *ada calon suami dan calon istri.* The second requirement is that the marriage must be made public by having two witnesses for each couple, and representatives (*wali nikah dan dua orang saksi)* from both families and the religious courts. The third requirement is an Islamic marriage contract or agreement that outlines the rights and responsibilities of the groom and bride and other parties involved in the marriage proceedings or licence or *ijab kabul* (Indonesian Ministry of Religious Affairs, 1991)

The rules for polygamous marriage, in the Quran, state "…marry those that please you of [other] women, two or three or four. But if you fear that you will not be just, then [marry only] one or those your right hand possesses"...[32] Islam allows up to four wives, providing the husband can treat his wives justly, and take care of his property and children, and provide his wives with social and economic support. Therefore, the husband as the breadwinner, must provide equal economic support, including a house, to meet the needs of each wife and family [33] (Indonesian Ministry of Religious Affairs, 1991; Mulia & Cammack, 2007; Nurmila, 2009). However, interpreting this verse as saying that polygamous marriage is restricted and even

---

[30] Al-Bayhaqi narrated in Shu'ab al-Eemaan from al-Raqaashi: "When a person gets married he has completed half of his religion, so let him fear Allah with regard to the other half (Hadits).

[31] The KHI covers three areas: marriage, inheritance, and Islamic charity (wakaf) (Indonesian Ministry of Religious Affairs, 1991; Indonesian President, 1991).

[32] See online Qur'an translation in An-Nisa (the women), verse 4, https://quran.com/4

[33] The Prophet Muhammad practised monogamous marriage for 20 years, but after the death of his first wife, Khadija Ra, the prophet practised polygamous marriage, for the purpose of tribal unity in Arabia. Marriage is a political symbol uniting different Arabic tribes and helped to spread Islam during that era (Mulia & Cammack, 2007; Nurmila, 2009)

prohibited as being unfair to wives, is considered challenging (Mulia & Cammack, 2007; Nurmila, 2009).

Marriage in Islam is considered as a sacred institution, and the dominant interpretation of polygamy is allowed in Islam, but it is restrictive. On the other hand, sexual relationships outside heterosexual marriage, such as promiscuity or pre-marital sex, adultery, fornication (*zina*), marital infidelity and homosexual practices, are prohibited and considered sinful (*dosa*), and believed to cause social and emotional problems such as homicide, the disintegration of a family, and various social problems[34] (Ebrahim, 2007; Hasnain, 2005; Ibrahim & Songwathana, 2010).

Islam, therefore, may provide a model of primary prevention for its believers, from illicit behaviours that put people at risk of HIV (Ebrahim, 2007; Hasnain, 2005; Ibrahim & Songwathana, 2010). However, not all Muslims may practise their religion, and some may break the rules by having sex outside marriage and extramarital affairs, using drugs, or having homosexual relationships (Andajani, et al., 2015; Bennett, 2005; Davies, 2015; Hasnain, 2005; Jacubowski, 2008; Najmah, Fajar and Sitorus, 2011; Platt, 2017; Rahmalia et al, 2015), which can lead to the spread of HIV among Indonesian women.

Being a good wife and mother

As the majority of participants in this study are Muslim women, they presented themselves as Muslim. In general, Muslim women are taught through Islamic religious and social upbringing—including the influence of Islamic leaders or preachers, their husbands and parents—to be obedient wives and good mothers after their marriage. Motherhood is a prestigious and high-status job in Islam as the hadith[35] states: “Paradise lies at the feet of the

---

[34] An interesting anecdote is presented in the story of Oneng, in Chapter 5 (page 140), whereby the honour of marriage was contested as the bringer of heartache and moral values for her husband. Oneng kept silent and did not provide any answers when a health worker asked her about Suleman’s past sexual behaviour, asking “whether had your husband used to see prostitutes”, after her husband was diagnosed with HIV. Oneng had to live bearing HIV and as a consequence, this silence resulted in her last child contracting the virus transmitted to her.

[35] Hadith is the words, actions, and silent approval of the Islamic Prophet Muhammad, messenger of God in Islam. This hadith “Paradise lies at the feet of the mother” is narrated by Ahmad Nasai, cited in Pappano and Olwan, 2016, p 1. Another hadith that support this messenger’s words is narrated by Bukhari Muslim, that said A man came to the Prophet and said, ‘O Messenger of God! Who among the people is the worthiest of my good companionship? The Prophet said: Your mother. The man said,

mother" (Pappano & Olwan, 2016, p. 1). In Indonesia, and for the majority of Muslims worldwide, a Muslim woman is expected to observe and incorporate rituals and guidelines regarding maternal beliefs and obligations into her childbearing life (Ayubi, 2019; Ibrahim & Songwathana, 2010; Isgandarova, 2016). All elements within motherhood and marriage, for example breastfeeding, pregnancy, obedience to a husband, and mutual sex fulfilment, are considered as worship of God (*Allah)* and obedience to His Messenger (the Prophet Muhammad) (Isgandarova, 2016).

As a good woman, a woman is not expected to be knowledgeable about sex, so inquiring into her partner's previous sexual behaviours may lead to her reputation as a badly behaved woman. The dominant interpretation of a man's role in Indonesia is as a virtuous and moral guide for his wife and a guide to Islamic values within their marriage (Ayubi, 2015, 2019; Bennett, 2005, 2015; Davies, 2019; Martin-Anatias, 2018b; Platt, Davies, & Bennett, 2018). Therefore, a woman's sexuality is private and not to be discussed with any other than her husband (Mulia, 2009; Nurmila, 2009); this may further inhibit women's ability to seek sexual health services, such as contraceptives, or having a test for STI or HIV, without the approval of her husband.

In summary, Indonesian women's status and roles cannot be separated from the gender and social norms embedded in the government regulations and Islamic values of Indonesian. In general, Indonesian women are shaped by the ideology of *ibuism*, monogamous registered marriages, and notions of family shaped by government regulations and dominant interpretations of marriage and motherhood in Islam, which are all patriarchal. Arguably, patriarchal values penetrate many different aspects of women's lives in Indonesia, including the interpretation of religious teachings, which in turn influence government policies and risk disempowering women as decision makers over their reproductive and health rights, thereby risking transmission of HIV to women and children. These elements, nevertheless, are also intertwined with how HIV-positive women, the participants in this study, see themselves in Indonesian society, and how they are perceived by health workers, NGO workers and policymakers, influencing how they may be stigmatised and discriminated against as HIV-

---

'Then who?' The Prophet said: Then your mother. The man further asked, 'Then who?' The Prophet said: Then your mother. The man asked again, 'Then who?' The Prophet said: Then your father" (Bukhari, n.d.).

positive pregnant women when accessing PMTCT services. The influences on women's expectations discussed in this section and societal reality of women in Indonesia, that may be associated with their HIV vulnerability, are discussed in the next section.

4. Societal Reality of women in Indonesia: Why women are vulnerable to HIV in Indonesia

As discussed above, societal expectations of Indonesian woman are a product of interactions of social norms that intersect with gendered ideology and gendered morality within a patriarchal society. This fourth section brings together literature on women's vulnerability to HIV, with evidence from Indonesian research. This section argues that intersectionality, or the confluence of all these socio-cultural, moral and religious factors, increase women's likelihood of getting HIV far beyond individual factors. The societal reality of Muslim women, in the patriarchal society in Indonesia with these risk factors, may contribute to a silent HIV epidemic among Indonesian women.

The discussion is divided into the following sub-sections: 1) HIV knowledge among Indonesian women; 2) sexual double standards; 3) fears of disclosure of sexual orientation and HIV status within heterosexual hegemony; 4) lack of condom use among married couples; 5) social inequality and stigmatisation of HIV-positive women; 6) institutionalised gendered discrimination in health settings; and 7) institutionalised gendered discrimination in governmental policies.

HIV knowledge among Indonesian women

The first societal reality of women that exacerbates women's vulnerability to HIV is that women may not know about HIV prevention and treatment, and may have misconceptions about HIV. A number of nationwide health surveys in Indonesia, such as the 2010 National Basic Health Survey (NBHS) and the 2012 Indonesian Demographic and Health Survey (IDHS) which were conducted in all 33 Indonesian provinces, reported that about 11.4% (n=91,433) and 12% (n=45,607) of women respectively, had a more comprehensive HIV/AIDS knowledge than men did (MoH, 2010; Statistics Indonesia, National Population and Family Planning Board, Ministry of Health, & Measure DHS ICF International, 2013). Among the women surveyed, less than six out of ten (about 40-60%) knew about mother-to-child transmission of HIV during pregnancy, delivery, and breastfeeding (MOH, 2010; Statistics

Indonesia et al., 2013). Women and men participated in the NBHS survey, and only 5.8% of women and 6.5% of men, had heard about VCT services (MOH, 2010)[36].

Socio-demographic factors may contribute to different levels of knowledge related to HIV, such as, the women's places of residence. A study by Angkasawati and Arifin (2010) noted that women living in low-HIV prevalence areas had a lower level of knowledge than those did in high-HIV prevalence areas. Furthermore, women with lower levels of education, living in rural areas, and who were unemployed, tended to have a lower understanding of HIV transmission compared to working women with better educations, living in urban areas (Angkasawati & Arifin, 2010). Arguably, the concentrated HIV programmes in provinces with high prevalence rates of HIV, as in Java, Bali, and Papua, may contribute to better understandings of HIV among women in these regions, compared to those in South Sumatra, which is considered as having a low prevalence rate of HIV.

There are profound effects of a lack of knowledge about HIV prevention and treatment and HIV vulnerability among Indonesian women. Despite the increase of literacy in Indonesia, most HIV programmes do not focus on women in the wider population, which may cause low HIV literacy. This sub-section reveals that a lack of health literacy of HIV, particularly among those women with low formal education levels and not working outside the house, may hinder women's abilities to make informed decisions regarding their health and HIV prevention. Therefore, *ibu rumah tangga* might think they are at low-risk of HIV infection or might not suffer from severe diseases after contracting HIV, and, as a result, do not see the need to access HIV prevention and treatment programmes for themselves or their children. If a woman has negative attitude to HIV, there seems little reason for her to volunteer to have an HIV test or choose condoms as her contraceptive method, particularly for a woman in the general population, such as a married woman. Later, in Chapter 5 and Chapter 6, I discuss examples of women who perceived themselves as having low risk of HIV infection, and discovered their HIV status at a very late stage.

---

[36] Of concern, is that women's misconceptions around HIV extended to beliefs that HIV could be transmitted by mosquito bites, supernatural powers, and sharing food from the same plates as HIV-positive people (Najmah et al., 2017; Statistics Indonesia, National Population and Family Planning Board, Ministry of Health, & Measure DHS ICF International, 2013).

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; Jacubowski, 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 couples[37] 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)

Consequently, by having unprotected sex, the majority of married women are at high risk of HIV infection, if their partners are exposed to high-risk HIV behaviours. Unfortunately, women are often not aware of this risk, and there is a common perception that it is women's, rather than men's, responsibility to take contraception (Nurmila, 2016). Men's participation in contraception as an HIV and STI prevention measure is still low in Indonesia, as it is worldwide (Higgins et al., 2010). In addition, non-consensual sex within wedlock may exacerbate the married women's risk to get infected to HIV. Male pre-assumption of sexual entitlement within marriage reflects the inability of many women to refuse sexual relationships within marriage (Idrus & Bennett, 2003). For example, among wives of husbands who were IDUs, women's lack of HIV knowledge, self-perceived low risk of HIV infection, unsafe sex practices and non-consented sex, all exacerbated their vulnerability (Damar & du Plessis, 2010; Idrus & Bennett, 2003; Imelda, 2015; Ismail et al., 2018). For this reason, the empowerment of women, exercising their reproductive and sexual health rights and their ability to make informed and independent decisions about contraceptive use, asserts the importance of condoms for safe sex practices, are all key to the prevention of HIV (IPPI 2017b; Nurmila, 2016). Later, in Chapter 5, I include the example of Mawar, who was HIV positive but continued to not use condoms during sexual intercourse with her HIV -negative partner.

Fears of disclosure of sexual orientation and HIV status within heterosexual hegemony

The fourth societal reality of women that increases women's vulnerability to HIV is heterosexual hegemony, which may lead to men's fears of disclosure to their wives of their MSM experiences and other high-risk behaviours (see Chapter 5, Mira's story:). Being MSM is perceived as 'abnormal' and 'sinful' within the discourse of heterosexual morality (Andajani, et.al., 2015; Stephen, 2015), hence, MSM in Indonesia may marry women to appear to adhere to heterosexual normality. To reduce the social risk of their 'gayness', MSM are generally not open about their sexual orientation in public spaces, or to their female partners (Stephen, 2015). Unfortunately, unsafe homosexual practices are considered to have contributed to the significant increase of HIV among MSM in Indonesia in recent years, despite the level of unsafe heterosexual practices (MoH, 2017b; Pisani, 2010; Praptoraharjo et al., 2016b). The risk of HIV transmission through anal sex is 18 times higher than that of vaginal sex without the use of a condom (Body Positive Inc, 2016, April 25), but the rate of condom use, which is effective for preventing HIV and other STIs, is very low amongst married couples and MSM (MoH, 2013e; Praptoraharjo et al., 2016b).

Social inequality and stigmatisation of HIV-positive women

The fifth societal reality of women that increases their vulnerability to HIV is that women with HIV in Indonesia, like those worldwide (Baral et al., 2013; Brawner, 2014; Higgins et al., 2010; Lin et al., 2007; Ostrach & Singer, 2012), suffer worse social impacts compared to those of HIV positive men, because of social inequalities. Women with HIV are thought to be 'unfaithful' wives, to have had sex outside marriage, committed a sin, or be working as a prostitute. These common beliefs may cause women to feel dirty, unworthy, or shameful, even though they may not have been involved in any of these behaviours. However, the evidence suggests that most women are known to be infected with HIV from their husband (Anindita et al., 2013; Butt, 2015; Damar & du Plessis, 2010; Hidayana, 2012; Hidayana & Tenni, 2015; Ismail et al., 2018; Rahmalia et al., 2015). These social determinants, mostly related to social shaming, stigmatisation, and gendered discrimination, further hinder women from presenting themselves to health services, in addition to their lack of knowledge on HIV prevention, and unprotected sexual practices.

Institutionalised gendered discrimination in health settings

The sixth societal reality of women that increases their vulnerability to HIV is the discrimination of WLWH by healthcare providers. In health settings, stigmatisation and discrimination amongst health workers towards PLWHIV, including women, is rampant. Mahajan et al. (2008) argued that discrimination against PLWHIV is a consequence of a stigma that leads to "the absence of objective justification" or bias (p. 5). It highlights the role of the subjectivity of each health professional who deliberately and consciously makes a distinction between HIV-positive women and other patients, in his or her attitude and approach (Mahajan et al., 2008). Studies regarding the level of HIV knowledge, stigmas, and discriminatory attitudes among healthcare workers in Indonesia by Waluyo, Culbert, Levy, and Norr (2015), with 225 nurses in Jakarta, and by Harapan et al. (2013), with 589 healthcare workers in Aceh, concluded that there were high levels of stigmatisation and discriminatory attitudes towards PLWHIV in Indonesia. Improving HIV knowledge, however, does not correlate with a reduction in discriminatory attitudes among healthcare workers such as midwives and nurses (Liem & Adiyanti, 2013; Waluyo et al., 2015). Thus, discrimination may become an institutionalised norm, if it is seen as a code of collective conduct within an institution, despite enhanced knowledge of HIV (Thompson, 2012; see also Chapter 3). If a woman self-stigmatises because of her HIV, with the double standards within gender relations and in an unsupportive environment of community and health workers, would she seek HIV information and HIV prevention?

Institutionalised gendered discrimination in governmental policies

The seventh societal reality of women that increases women's vulnerability to HIV is the policies put women at risk of being more susceptible to HIV than men. I outline two examples of how health and legal regulations may protect key population groups, but may decriminalise key populations, so these groups may hide their high-risk behaviours related to HIV to their female partners such as wives.

Policies may create a greater risk of vulnerability to HIV for women than for men. Some can be counterproductive or discriminatory to women and other marginalised groups. Effective and responsive health public policy, however, can help prevent HIV in married women and mothers passing HIV to their babies. Within conservative regulations in Indonesia, nevertheless, there is a conflict between regulations in the Ministry of Health, and legal regulations (see MoH regulations in Chapter 3) related to norms in each province in Indonesia, as well as with international human rights policies[38].

National regulation, marriage law number no 1 in 1974 in Indonesia, only accommodates heterosexual marriage, and acknowledge the existence of only the binary sexes of female and male (Arivia & Boangmanalu, 2016). Therefore, homosexual relationships are considered both illegal and immoral in Indonesia. All activities that contribute to immoral behaviour, such as homosexuality, IDUs, sex workers, have to be monitored by local government, law enforcers, parents, public figures (*tokoh masyarakat*) and lawyers (Chapter IV, article 3)[39] (South Sumatra

---

[38] The Government of Indonesia has passed some regulations related to HIV, to protect women and provide health rights for marginalised groups. For example, a regulation of the Indonesian Ministry of Health, number 43 in 2016 (article 12), as discussed in Chapter 3, states that every health service should provide standard HIV services for not only pregnant women and tuberculosis patients, but also STI patients, transgender women, drug users, and prisoners (MoH, 2016). Another example is in Law number 35 in 2009, that highlights that drug users (*pecandu*) and the victims of drug use (*korban penyalahgunaan narkotika*) can access medical and social rehabilitation (Chapter 17, article 127 &128) (Indonesian Parliament and President of Indonesian Republic, 2009).

[39] The Aceh government has passed Sharia's law, known as Qanun Jinayat (*Hukum Jinayat*), to regulate punishment for alcohol use, child abuse, sexual harassment and rape, and also same-sex practice (MSM-*liwath*; lesbians-*musahaqah*) (Chapter II, article 3). The aim of Qanun Jinayat is to protect human rights within a Muslim context and prevent the spread of immoral behaviours in general populations in Aceh (see Governor of Aceh, 2014)

Governor, 2002). Consequently, there are conflicts in Indonesia between the notions of protecting the rights to health for key populations, and the norms and public views of morality on behaviours of those considered as minority groups (Andajani et al., 2015; Arivia & Boangmanalu, 2016). Thus, this tension may contribute to HIV transmission to women in the general population and their children, as discussed in the section on the fourth societal reality of women.

To conclude, there are profound effects of a lack of knowledge about HIV prevention and treatment and HIV vulnerability among Indonesian women. Previous Indonesian health surveys discussed in this section reveal a lack of knowledge related to HIV, HIV testing, and HIV transmission in pregnancy, delivery, and breastfeeding. Therefore, *ibu rumah tangga* might think they are at low-risk of HIV infection or might not suffer from severe diseases after contracting HIV, and as a result, do not see the need to access HIV prevention and treatment programmes for themselves or their children. Women often do not want to be tested for HIV because of fears of stigmatisation, social-shaming (*rasa malu*), and the loss of face (*jaga muka*). Unfortunately, men's participation in HIV prevention is still low in Indonesia, as it is worldwide (Higgins et al., 2010). I suggest that gender norms and gender discrimination in the private and public spheres in the Indonesian context may contribute to HIV vulnerability among Indonesian (married) women and increase the risk of mother-to-child transmission of HIV with less access to PMTCT services.

5. Summary

The intersection of individual, intimate, social/community and policy spheres within social, cultural, religious, political, and legal regulatory determinants may make women vulnerable to HIV. The intersectionality of these spheres should be considered as central to women's vulnerability, especially in ways that women's roles and responsibilities are domesticated and in relation to the social stigma surrounding HIV. Understanding HIV vulnerability among women in Indonesia means understanding women's position in a wider social and gendered relations context. The highest increase in HIV infections is found in women out of the identified risk groups. This fact demands an urgent challenge to existing HIV policies and strategies to ensure that women have the right support and access to HIV prevention care.

Women living with HIV are at risk of social stigma and discrimination, as HIV is largely seen as a sinful disease, that only those with bad sexual behaviours (such as prostitutes, and those having multiple sexual partners outside marriage) ought to have; this view continues to be largely socially accepted in Indonesia. Interestingly, this is not an unusual phenomenon experienced by women living with HIV in Indonesia, but is worldwide. Debate on women's HIV vulnerability needs to be centred around political commitment to promote gender equity across different sectors; for example, equal access for women's sexual and reproductive health, and non-discriminatory practices in Indonesian marriage laws and religious teachings, thereby enabling women's voices to be heard and experiences regarding HIV strategies.

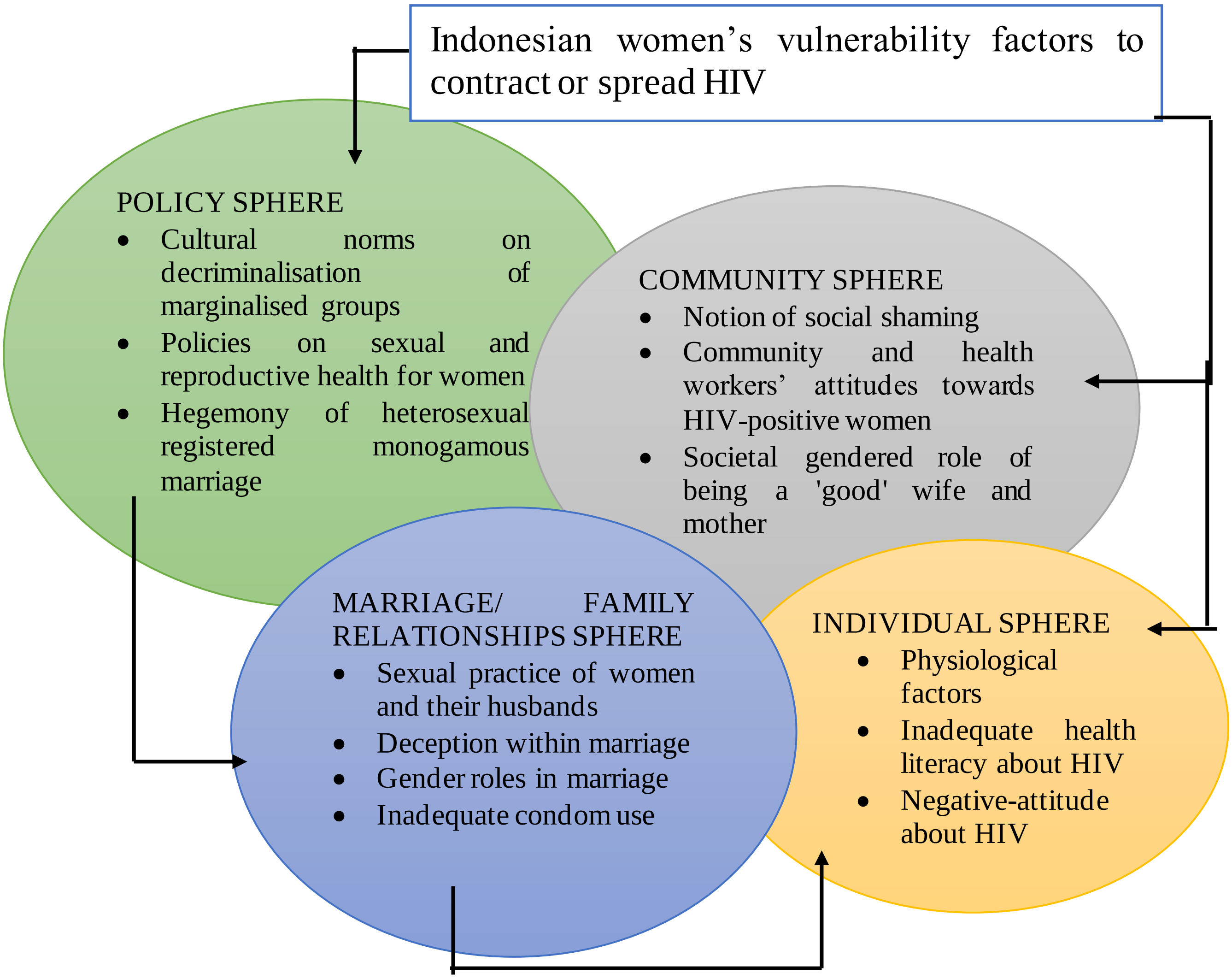


Figure 2.2: Spheres of women's vulnerability to HIV infection in Indonesia

Note: This framework of intersectionality is based on reflections on studies discussed in Chapter 2. In Chapter 5 (see Figure 5.4), I provide evidence to support this framework.

Finally, HIV vulnerability among married women is complex and influenced by many factors: the life context of the woman, her personal beliefs, attitudes, knowledge of HIV, sexual practices within marriage, the support available from her husband and family network, and other wider social and political and regulatory elements. This fact places an urgent challenge to existing HIV policies and strategies to ensure that women have the right support to avoid transmitting HIV to their babies. It is also important to have an understanding of how discrimination within existing policy may reinforce existing gender norms and discriminatory religious teachings within the intimate and individual spheres, particularly in accessing Prevention of Mother to Child of HIV transmission. This is reviewed in Chapter 3.

Chapter 3. Prevention of mother to child transmission of HIV: A global and Indonesian context

1. Introduction

The first two chapters show that women, particularly wives and mothers, were nearly invisible at the beginning of the HIV and Aids epidemic in the 20th century. Chapter 1 provided an overview of my research topic and the significance of my research. It showed a need for early diagnosis of HIV among mothers and wives to prevent HIV from mother-to-child transmission and the urgency of enabling HIV-positive pregnant women to access health services. One form of HIV care that focuses on averting HIV among children is through PMTCT services. Chapter 3 presents literature regarding PMTCT of HIV and the global public health achievements to eliminate perinatal HIV transmission.

PMTCT is a global strategy to eliminate HIV among children through mother-to-child transmission of HIV, to ensure HIV-positive mothers are alive and healthy, and to provide quick access to HIV care for HIV-positive children. PMTCT was introduced in the early 20th century in different parts of the world in order to achieve the Millennium Development Goals (MDGs)[40] of eliminating the spread of HIV-AIDS, particularly among mothers and children (Chersich, Newbatt, Ng'oma, & de Zoysa, 2018; Idele et al., 2017; Phanuphak & Phanuphak, 2016; United Nations, 2000).

In line with this global movement, the WHO formulated a four-pronged comprehensive PMTCT strategy. Prong 1 focuses on the prevention of HIV in reproductive-aged women through the provision of antenatal HIV testing. Prong 2 aims to prevent unintended pregnancy among HIV-positive women and their spouses by providing information and choice of family planning, and prong 3 focuses on preventing mother-to-child HIV transmission among HIV-positive pregnant women. Prong 4 provides on-going social and psychological support and availability of ARV medicines for children, their mothers and partners living with HIV.

---

[40] MDGs include: "to have reduced maternal mortality" (point 4), and "under-five child mortality" (point 5) and "to have, by then halted and begun to reverse the spread of HIV/AIDS" (point 6) (United Nations, 2000, p. 5).

The PMTCT four-pronged strategy focuses on women who have, or are at risk of contracting HIV. The programmes generally include the early detection and prevention of HIV in pregnant women through spreading information related to PMTCT and providing confidential testing. When a pregnant woman is tested and found to be HIV positive, then PMTCT services provide ARV medicines to prevent vertical transmission from the woman to her unborn child during pregnancy, delivery, and/or breastfeeding, and is followed by appropriate breastfeeding practice (breastmilk substitute such as milk formula). If a child is diagnosed with HIV, ARV therapy should be accessible to prevent AIDS-related death (Idele et al., 2017).

This chapter is divided into two parts: PMTCT at the global level, and PMTCT in Indonesia. I argue that understanding PMTCT provides insights into the success and challenges of the programmes in order to provide better PMTCT services, particularly in Indonesia, the study context.

2. PMTCT at a global level

This section discusses the preparation, programmes, implementation, and challenges of PMTCT—past and present—at a global level. It addresses how PMTCT services in limited-resource countries are driven by international donor-programmes and may fail to accommodate the multi-layered complex socio-cultural and political context of women’s lives, and the ability of 23 prioritised countries for PMTCT, mostly resources-limited countries, to meet the conditions stated in the recommendations. This section contains three parts: 1) an overview of the history of PMTCT: 1994-2013; 2) what we know about the programmes in 2013-2017 and who the main players are; and 3) barriers to accessing PMTCT services.

A global history of PMTCT: 1994-2013

In this section, I discuss when PMTCT came about and what happened between 1994 and 2013. Table *3.1* provides an overview of the history of PMTCT.

Table 3.1: PMTCT global history, 1994-2013

Category	1994-1996	2000	2010	2013
First adoption of PMTCT programmes	Developed countries and one developing country (Thailand)	HIV-epidemic countries (mostly sub-Saharan)		
Evolution of key indicators of PMTCT programmes		**Phase 1.** Preparation, monitoring and establishment of PMTCT **Phase 2.** Follow up and care for HIV-positive mothers and their children		**Phase 3.** Life-long ARV therapy for all HIV-infected pregnant and breastfeeding women
ARV therapy[41]	Trials on different ARV medicines	Option A		Option A or B Option B or B+

Sources: Chersich et al., 2018; De Cock et al., 2000; Idele et al., 2017; Phanuphak & Phanuphak, 2016

When PMTCT came about - global context

Multiple clinical trials of effective medicines were conducted in the 1900s to provide evidence of reduction risk of HIV from HIV-positive pregnant mothers to their unborn children. In 1994, a successful clinical trial of provision of biomedical therapy (regimen of zidovudine) provided positive evidence for the establishment of PMTCT programmes (Connor et al., 1994; Van de Perre, Tylleskär, Delfraissy, & Nagot, 2013). Other clinical trials of differing ARV medicines were reported between 1900 and 2000 (De Cock et al., 2000). However, the response and achievement of PMTCT coverage has differed between developed and developing countries.

---

[41] **Option A:** For HIV-positive pregnant women with CD4< 350 cells/mm^3: the intervention of Zidovudine (AZT) to mothers prophylactically during pregnancy; single-dose of nevirapine (NVP) to both mother and the infant at delivery; maternal AZT and lamivudine (3TC) to mothers during the first week postpartum.

Option B: For all HIV-positive pregnant women, regardless of CD4 counts: the intervention of a triple ARV medicine during pregnancy and breastfeeding; six weeks of daily NVP for the infants, regardless of infant feeding.

Option B+: For all HIV-positive pregnant women, regardless of CD4 counts: the therapy of a triple ARV regimen during pregnancy and continuing for life.

Some PMTCT services have been administrated in developed countries since 1994 (Lindegren et al., 1999). These countries, such as European countries, Australia and the United States, have provided regular evaluations of PMTCT services (Chersich et al., 2018; Lindegren et al., 1999; Nesheim, Harris, & Lampe, 2013; Sollai et al., 2015). After 2000, updated PMTCT programmes were implemented in developed countries, with no considerable change or revisions of the standard of PMTCT programmes; for example, regular antenatal HIV testing for all pregnant women, life-long ARV therapy, and other holistic prevention approaches beyond biomedical therapy (Chersich et al., 2018; Lindegren et al., 1999; Nesheim et al., 2013; Sollai et al., 2015).

PMTCT in developing countries was considerably slower and initiated only prior to 2000, particularly in HIV-epidemic countries (Idele et al., 2017; Phanuphak & Phanuphak, 2016). The high price of Zidovudine was not affordable in limited-resource countries (Idele et al., 2017; Phanuphak & Phanuphak, 2016). Consequently, some countries, such as in Asia and Africa, depended on international donors to implement PMTCT services based on a single dose of Zidovudine (De Cock et al., 2000; Idele et al., 2017).

In the Asian continent, Thailand was the first Asian country to reduce perinatal HIV transmission to less than two percent (Phanuphak & Phanuphak, 2016). Thailand was a pioneer for implementing PMTCT by providing free-standard Zidovudine (since 1996) for any hospitals that treated HIV-positive pregnant women (Phanuphak & Phanuphak, 2016). A strong commitment from the Thai Government, as well as good support of antenatal care system infrastructure (such as, clean water and 95% of deliveries occurring in healthcare facilities) and additional support from international agencies, enabled Thailand to eliminate perinatal HIV transmission a decade ago (Amornwichet et al., 2002; Phanuphak & Phanuphak, 2016; Priest, 2017; Thisyakorn, 2017; UNAIDS, 2018). In the first decade, many developed countries and other middle-income countries had significant success in revising mother-to-child HIV transmission. However, for other countries, mostly sub-Saharan, it has remained a challenge.

What happened between 2000 and 2013?

Globally, there are three main phases or key indicators of PMTCT programmes (Idele et al., 2017), as shown in Table 3.1. The first phase (2000-2005) focused on the preparation of the establishment of healthcare providers in many countries (Chersich et al., 2018; Idele et al., 2017). The outputs were: the availability of PMTCT guidelines, availability of trained health workers, increasing numbers of health facilities based on PMTCT, reported numbers of pregnant women tested for HIV, and reported numbers of HIV-positive women accessing ARV therapy for PMTCT services. The second (2006-2010) and third phases (2010-2013) focused on follow-up and care of HIV-positive pregnant women and postpartum mothers and their infants and the monitoring of life-long ARV therapy to all HIV-positive pregnant and breastfeeding women respectively. Monitoring and evaluation of PMTCT programmes provides evidence of the effectiveness and simplicity of ARV[42]. At least four revisions of the WHO PMTCT guidelines have occurred in the last decade, recommending the provision of lifelong ARV therapy, regardless of the CD4 cell count, to all children, adolescents, and adults, including all HIV-positive pregnant and breastfeeding women (Chersich et al., 2018; Idele et al., 2017; WHO, 2006, 2007, 2010, 2013).

Some critiques on the quick change of ARV therapy choice for pregnant women have been noted. The change in recommendation of Option B to Option B+ involved clinical research trials, but it may have been driven by other considerations, such as lobbying among key players of PMTCT programmes, a need of quick action for scaling up option B+ for other national policy programmes, and the availability of donor funding for the implementation of Option B+ (Chersich et al., 2018). However, an insider of PMTCT programmes argued that consideration

---

[42] The differences between PMTCT protocols Option A, B and B+ (Chersich et al., 2018; O'Brien, Shaffer, Sangrujee, & Abimbola, 2014):

PMTCT protocol Option A offers a cheaper intervention to reduce mother-to-child transmission compared to Option B and B+. However, the drawbacks of Option A are the complexity of different types of medicines during pregnancy, delivery, and breastfeeding, and a need for a CD4 test to determine the uptake of PMTCT services (eligibility, HIV-positive pregnant women with CD4 <350 cells/mm3).

Compared with Option A, a PMTCT protocol with Option B provides an opportunity to increase accessibility to PMTCT services as there is no requirement for a CD4 test and similar ARV drugs are introduced during pregnancy, delivery and breastfeeding. Yet life-long ARV is still a choice in Option B and may result in delays on the use of life-long ARV after their delivery.

The latest recommendation is the PMTCT protocol with Option B+ that provides life-long ARV therapy for all HIV-positive pregnant women without the requirement for a CD4 test. This option provides solutions for HIV-positive women with repeated occurrence of pregnancy, particularly in a setting with unmet family planning needs. Additionally, Option B+ enhances maternal health and prevents the risk of AIDS-related diseases and mortality due to delaying HIV treatment for HIV-positive women. Option B+, nevertheless, needs further consideration in each country. Option B+ is life-long ARV and is much more expensive. It requires long-term adequate availability of ARV and access to financial support to adopt this option, particularly in resource-poor settings.

of the simplicity of Option B+ was based on: "health workers' and health system's point of view" (Chersich et al., 2018, p. 7). Thus, PMTCT in developing countries needs to accommodate the readiness of health systems and the complexity of women's lives in each setting.

Global PMTCT programmes in 2013-2017

Having discussed the journey of PMTCT in the first decade of establishment, this second part reviews global PMTCT programmes between 2013 and 2017. I have identified three main themes for this section: 1) WHO: Four-prongs of PMTCT services; 2) UNAIDS[43] or The Joint United Nations Programme on HIV and AIDS: Start free, stay free, AIDS free; and 3) key PMTCT programme players.

World Health Organisation: Four-prongs of PMTCT services

As stated in the introduction, comprehensive PMTCT programmes have been formulated into a four-pronged strategy (WHO, 2007, 2010, 2018). After the introduction of the four-pronged PMTCT strategy, Prong 3—the biomedical approach—became the main focus of PMTCT programmes for many decades. Without treatment, 20-50% of HIV-positive pregnant women transmit the virus through vertical transmission to their infants (De Cock et al., 2000; MoH, 2013a; Tudor Car et al., 2011). Accessing biomedical therapy (such as ARV medicines) and other interventions as part of PMTCT Prong 3 services, can reduce the likelihood of an infant born to an HIV-positive mother getting infected to HIV, to below five percent (WHO, 2019b).

An emphasis on Prongs 1 and 2 has been lacking globally (Hairston et al., 2012). Arguably, HIV prevention during pregnancy and HIV testing of all pregnant women are particularly important. Recent evidence shows that a mother or woman of reproductive age who acquires HIV during her pregnancy or postpartum period is more likely to pass the infection to her infant than a mother with a chronic HIV/infection (Drake et al., 2014). Therefore, all four prongs should work holistically to enhance access to PMTCT services, particularly among women of reproductive age in the general population.

---

[43] UNAIDS unites of 11 United Nation organisations, including UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, UN Women, ILO, UNESCO, WHO, and the World Bank.

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 services[44] (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 programmes[45] 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'Ivore, 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).

International Children's Emergency Fund (UNICEF), UNAIDS, and the Inter-Agency Task Team (IATT) (Chersich et al., 2018; Idele et al., 2017).

Table 3.2: Key players of PMTCT programmes, and their main roles

Key players	Main roles
WHO	Provides HIV treatment guidelines and revises recommendation of ARV for treating pregnant women and preventing HIV infection in infants
UNICEF	Focuses on providing critical recommendation of PMTCT programmes and paediatric HIV interventions
UNAIDS	Performs regular monitoring of the declaration of commitment on HIV/AIDS: guidelines on construction of core indicators, including a global plan for eliminating mother-to-child HIV transmission in 2011, and the global plan of Start Free Stay Free AIDS-Free in 2016
IATT	Combines mostly international donors for PMTCT programmes (such as Global Fund, World Bank, and USAID) to provide support and funding to scale up PMTCT programmes, particularly in resource-limited countries

Source: Idele et al. (2017)

Since the beginning of the 21st century, these four organisations have worked together to provide countries with the skills and resources to harmonise monitoring and reporting, and providing universal access reporting[46] (Idele et al., 2017). For example, the WHO and UNICEF (2016) created guideline updates for HIV and infant feeding to improve feeding practices among mothers living with HIV. Between 2013-2015, the WHO and UNAIDS (2013, 2015) also recommended HIV sentinel surveillance (HSS) on pregnant women accessing antenatal clinics, to perform early diagnosis of HIV and early access for PMTCT services for the women. Additionally, three key players, the WHO, UNICEF and UNAIDS, have provided regular reports of PMTCT programmes and the achievements to IATT, including recommending the latest update of life-long ARV therapy for pregnant women at a global level, as well as requesting funding to support this global plan (Chersich et al., 2018; UNAIDS, 2017).

Multiple key players, however, can result in complex monitoring and evaluation. Unfortunately, many countries, including Indonesia, still lag behind in their ability to provide six-monthly reports of PMTCT data on specific age groups for ARV users, due to poor

---

[46] Through using data across online Excel-based reporting tools between 2011-2013 and through Global Aids Response Progress Reporting (GARPR) through online platforms in 2014-2016.

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.

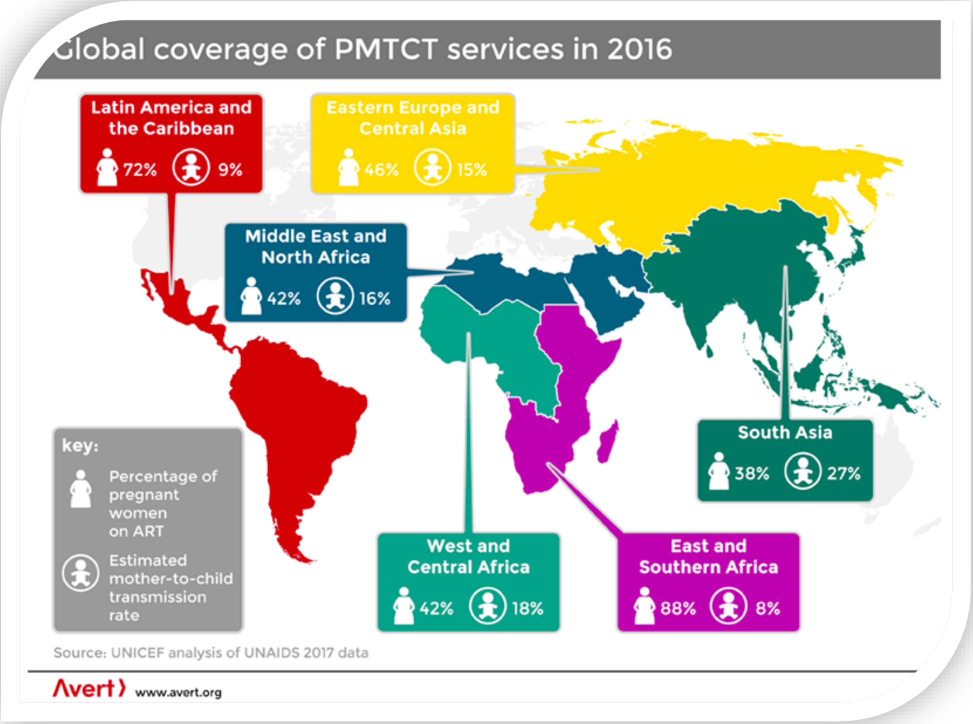


Figure 3.1: Global coverage of PMTCT services in 2016

Note. Reprinted from *Prevention of Mother-to-Child Transmission (PMTCT) of HIV*, by Avert, 2009, United Kingdom. Copyright (2019) by Avert.

Source: UNICEF, UNAIDS (2017)

A significant impact of the low coverage of PMTCT services is the failure to prevent the occurrence of HIV-positive children. Globally, HIV-positive children (0-14 years) accounted for 1.8 million (1.3-2.4 million) in 2017, despite the increase of numbers of PMTCT services worldwide (UNAIDS, 2017). Between 2016 and 2017, the number of children that had become infected with HIV increased from 160,000 to 180,000 cases, and there are up to 505 new HIV-infected children every day worldwide (Ishikawa et al., 2011; WHO, 2010). Up to 90% of children contract HIV from vertical transmission, while less than 10% of the cumulative cases are from sexual abuse by adults with HIV (Ishikawa et al., 2011; WHO, 2010). The majority of HIV-positive children are living in the sub-Saharan region; the high number of the children living with HIV could be considered as a proxy factor of low coverage of PMTCT services.

Arguably, women's participation and access to PMTCT services and women's literacy on HIV prevention and services are key to the success of PMTCT programmes and reduction of new HIV infections in children. In 2017, for example, about 1.4 million pregnant women with HIV required PMTCT services (WHO, 2019b). Without addressing the multiple barriers to accessing PMTCT services, HIV-positive pregnant women, who may not perceive themselves to be at risk of contracting HIV, are more likely to transmit the virus to their children, with or without awareness of their HIV status. This condition may result in HIV continuing to be the first global burden of disability.

Barriers to access PMTCT services at global level

As noted previously, the coverage of PMTCT services is still low in many parts of the world, particularly in poor-resource countries (see Figure *3.1*:). For example, only one out of ten pregnant women who tested HIV-positive in integrated antenatal and PMTCT services accessed safe labour practice in Malawi; and one out of three HIV-positive women accessed ARV during pregnancy in Nigeria, despite free access to maternity services or ARV therapy (Kasenga, Byass, Emmelin, & Hurtig, 2009; UNAIDS, 2017). The WHO noted four categories of barriers that need to be addressed to increase the accessibility of health services: health system or physical, economic, information, and cultural barriers (Evans, Hsu, & Boerma, 2013; WHO, 2002, 2019a).

Health systems barriers

The first challenge of accessing PMTCT is an inadequate supportive health system. Health system barriers may relate to the availability of relevant and quality services within reach, opening hours, appointment systems and service organisation (Evans et al., 2013). In my review, I have identified three main barriers to accessing PMTCT services at a global level: (1) poor clinic facilities; (2) unfair treatment in health services; and (3) poor quality of HIV training.

The first health system barrier is poor clinic facilities for HIV testing and ARV provision. In generalised epidemic countries, HIV prevalence exceeds one percent among pregnant women. HIV testing is routine for pregnant women, yet women may be afraid to access HIV testing outcomes due to a perceived stigma or their partner’s disapproval (Blackstone, Nwaozuru, & Iwelunmor, 2018). In concentrated epidemic countries, HIV prevalence is over five percent in the key population at higher risk (e.g IDUs, sex workers, and MSM), but less than one percent amongst pregnant women, for example, in Vietnam and Indonesia (UNAIDS, 2015). HIV testing is usually offered earlier in pregnancy to a suspected case related to high-risk HIV behaviours; for example, for a female sex worker or a female IDU or a woman exposed to behaviours related to HIV (Oosterhoff, Hardon, Nguyen, Pham, & Wright, 2008; Wulandari et al., 2019). Although HIV testing is easy to access in generalised epidemic countries, compared to countries with concentrated epidemics, both have insufficient supplies of ARV (Bijker et al., 2017; Busza et al., 2012; Hampanda, 2012; Hardon, Oosterhoff, Imelda, Anh, & Hidayana, 2009; Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008).

The second key health system barrier is unfair treatment in health services. Lack of professional and irresponsive services have made women feel uncomfortable and fearful of coming to a clinic in limited-resource countries (Busza et al., 2012; Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013). Examples of abuse and disrespectful services may include discriminatory practice to women living with HIV, including the negative attitude of a health worker during counselling and provision of care, avoidance of providing health services for HIV patients, breach of women's HIV status and confidentiality, and being tested for HIV without informed consent (Darak et al., 2012; Nguyen, Oosterhoff, Pham, Hardon, & Wright, 2009; Panditrao, Darak, Kulkarni, Kulkarni, & Parchure, 2011; Turan & Nyblade, 2013). Additionally, high workloads amongst health workers may impact on their professional ability to provide PMTCT services, as well as the poor readiness of healthcare providers in implementing quick changes on ARV therapy (Chiya, Naidoo, & Ncama, 2018).

The third key health system barrier is the lack of appropriate HIV training for healthcare providers regarding women's rights to access PMTCT services. A lack of HIV-related training among health workers may result in their having negative attitudes toward HIV positive women, poor decision-making by the health providers, providing inaccurate information to the women and families, and their failure to refer women to access timely PMTCT services (Darak et al., 2012; Nguyen et al., 2009; Turan & Nyblade, 2013). These three health system barriers are interlinked and limit women's access to PMTCT services.

Economic barriers

Women's decisions to access PMTCT services, regardless of free services[47], is also influenced by their family's financial situation. Economic accessibility or affordability means "influenced by the wider health financing system by household income" (Evans et al., 2013, p. 546). In my

---

[47] In sub-Sahara and Asian countries such as Vietnam, India, and Indonesia, HIV testing and ARV are free at public healthcare providers.

review, two economic barriers at the global level to accessing PMTCT services were identified: being poor; and a fragmented health system disadvantaging poor women.

The first economic barrier is that many HIV-positive women are poor as well as economically dependent on their husband. This can severely limit women's ability to make decisions regarding health and access to health services, including PMTCT services (Hampanda, 2012; Hlartaithe, Grede, de Pee, & Bloem, 2014). Nevertheless, not many developing countries have state-based universal coverage or social insurance (Lagomarsino, Garabrant, Adyas, Muga, & Otoo, 2012; Tangcharoensathien et al., 2011). Arguably, without the state-managed social safety net and universal health insurance, poor women and families are left to decide how to afford PMTCT services (Hlartaithe et al., 2014).

The second economic barrier is a fragmented health system that disadvantages poor women, particularly related to indirect costs (such as transportation and time associated with waiting in health settings), which may influence women's decisions in relation to accessing health services such as PMTCT clinics (Busza et al., 2012; Nguyen, Oosterhoff, Ngoc, et al., 2008). A study by Kanengoni, Andajani-Sutjahjo, and Holroyd (2019) noted that women in poor villages in Zimbabwe were required to bring their own food, wood, and disposable materials (i.e., gloves and cotton pads) when staying at maternity waiting homes. For women attending PMTCT clinics, transportation costs include coming to the clinic for HIV testing, returning to collect the test results, and then regular consultation for ARV (Busza et al., 2012; Gourlay et al., 2013; Hlartaithe et al., 2014).

Information barriers

Women need to get the right information about and knowledge of symptoms of HIV, as well as information about HIV transmission, prevention, and services available, to facilitate their uptake of PMTCT services. Thus, relevant and timely information is key to women's ability to make informed decision with regard to services. Information accessibility refers to women's rights to seek, receive, and impart information and ideas concerning health issues and, at the same time, protect women's rights to confidentiality and non-discrimination (WHO, 2002, p. 13). In my reviews, two intersecting information barriers to accessing PMTCT services were apparent: (1) inadequacy of well-trained counsellors; and (2) women afraid to ask for information.

The first key information barrier to be discussed is the lack of well-trained counsellors, as this may contribute to poor patient-provider communication and interaction. Consequently, HIV-positive women may lack an understanding of PMTCT services— how to access it, and what to expect from such services — even after being exposed to healthcare providers based at PMTCT services (Hampada et al., 2012). For example, a pregnant woman with HIV needs to understand the symptoms of HIV, and the effects and side effects of ARV therapy to comply with the prescribed medicines, particularly life-long ARV (Option B+) (Hlartaithe et al., 2014). However, stigmas surrounding HIV in health services may prevent dissemination of correct information and knowledge about HIV and PMTCT services (Gourlay et al., 2013; Hlartaithe et al., 2014; Nguyen, Oosterhoff, Ngoc, et al., 2008).

In addition to poor quality counselling, a second key information barrier is that women may be afraid to ask for HIV related information if it is not understood during counselling. Generally, there is a lack of information about PMTCT services, family planning, and the side effects of ARV therapy in health settings (Hlartaithe et al., 2014; Nguyen, Oosterhoff, Ngoc, et al., 2008). Thus far, the first three barriers to accessing healthcare-based PMTCT services, health systems, and economic information, have been reviewed.

Cultural barriers

Globally, there are two main cultural barriers to women accessing PMTCT services: 1) the stigma attached to HIV means women face multiple fears; and 2) gender discrimination in health settings compromises women's rights in relation to their own health. Cultural accessibility of health services refers to people's willingness to seek services which do not discriminate on the basis of social, or cultural norms and values, in relation to gender, age, religion, and ethnicity (Evans et al., 2013). Barriers to women accessing PMTCT services are largely related to the cultural, political, and religious contexts in which they live, as well as their social status and position within their family networks (Gulliford et al., 2002).

The first key cultural barrier is that stigmas and discrimination against people living with HIV may result in multiple fears about accessing PMTCT services (Blackstone et al., 2018; Turan & Nyblade, 2013). Strong socio-cultural and religious stigmas against women with HIV, expressed in words such as 'sinful' and 'immoral', extend to all HIV related services (Busza et al., 2012; Butt, 2015; Hlartaithe et al., 2014; Nguyen, et al., 2008; Turan & Nyblade, 2013). Consequently, a woman may be fearful of HIV testing and receiving positive results (Blackstone et al., 2018; Busza et al., 2012; Hampanda, 2012; Hlartaithe et al., 2014; Nguyen, 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.

This section discusses PMTCT programmes in Indonesia: successes and challenges. It is divided into four parts: 1) history of PMTCT in Indonesia; 2) programmes on offer in 2013-2017; 3) MoH regulations in 2013-2017; 4) key PMTCT players in Indonesia; and 5) barriers to accessing PMTCT services in Indonesia.

History of PMTCT in Indonesia

Understanding PMTCT in the past informs the improvement and challenges of PMTCT in Indonesia in the present. This section considers the history of establishing and improving PMTCT services throughout Indonesia.

As noted earlier, rapid global PMTCT changes are well reflected at country level, including in Indonesia. In 2011, the Indonesian Government signed an agreement of the United States Assembly Special Session on HIV/AIDS (UNGASS) to enhance the national commitment to provide a strategic and national plan to prevent HIV/AIDs and to achieve MDGs (Idele et al., 2017; Imelda, 2011). However, the first implementation of PMTCT in Indonesia was initiated by an NGO in Jakarta—*Yayasan Pelita Ilmu* or YPI—in 1999 and then extended into six provinces in Indonesia with high-HIV prevalence in 2007 (Imelda, 2011).

Two decades after the first AIDS cases in 1987 in Indonesia, and five years after the first National Strategy in 1994 (MoH, 2013c, 2015b), the Indonesian MoH prepared for the implementation of PMTCT at national level. In 2006, YPI and the Indonesian MoH worked together to formulate the first PMTCT guidelines (Imelda, 2011). Between 2004 to 2008, the main focus of MoH included providing training for PMTCT teams, improving reporting procedures of the programmes, and setting up PMTCT services in hospitals in each province (MoH, 2013c, 2015b).

There was also an increasing number of hospitals offering PMTCT services in Indonesia. For example, in 2011, there were only 94 PMTCT services, which increased five-fold to 478 PMTCT services—108 in hospital-based services, and 270 in primary health care services or *puskesmas* (MoH, 2015b). The establishment of PMTCT services, nevertheless, has been very slow in Indonesia despite the government's efforts to increase coverage. Until 2013, PMTCT services primarily focused on pregnant women who were suspected of practising unsafe sex or other high-risk behaviours, female sex workers and female IDUs, and women with partners in high-risk groups related to HIV. For the first decade, PMTCT services, and trainings become a priority, mostly in Java island and Papua (MoH, 2015b). For example in 2013, PMTCT training prioritised only 12 provinces with high numbers of HIV cases, out of 34 provinces in Indonesia (MoH, 2015b).

The main focus of these PMTCT programmes may contribute to inequality of service provision. Most provinces with low numbers of HIV cases, such as Palembang, the study setting, have on average, only one or two hospitals providing PMTCT services, while provinces with high numbers of reported HIV cases provide at least six (for example, Bali has 6 hospitals, DKI Jakarta has 23, East Java has 19, and West Java has 13 hospitals). The highest HIV-epidemic area in Indonesia, there are 23 hospitals in West Papua, and 83 in Papua provinces (MoH, 2018). Arguably, for a variety of reasons, an increasing number of health facilities offering PMTCT services does not mean that more pregnant WLWH have access (Badriah et al., 2018; Hardon et al., 2009; Lumbantoruan et al., 2018).

Programmes on offer between 2013-2017

This section provides an overview of the four-pronged strategy of PMTCT services in Indonesia according to the 2015 PMTCT guideline (MoH, 2015b). Indonesian MoH, as the main player of the Indonesian Government in relation to health, follows the WHO's four-pronged strategy of PMTCT services. I have divided this section as follows (see Figure *3.2*).

- **Prong 1:** Prevention of HIV among women of reproductive age
- **Prong 2:** Preventing unintended pregnancies among HIV-positive women
  Prong 3: Preventing HIV transmission from a HIV-positive woman to her unborn baby
- **Prong 4:** Providing appropriate treatment, care, and support to mothers living with HIV, and their children and families.

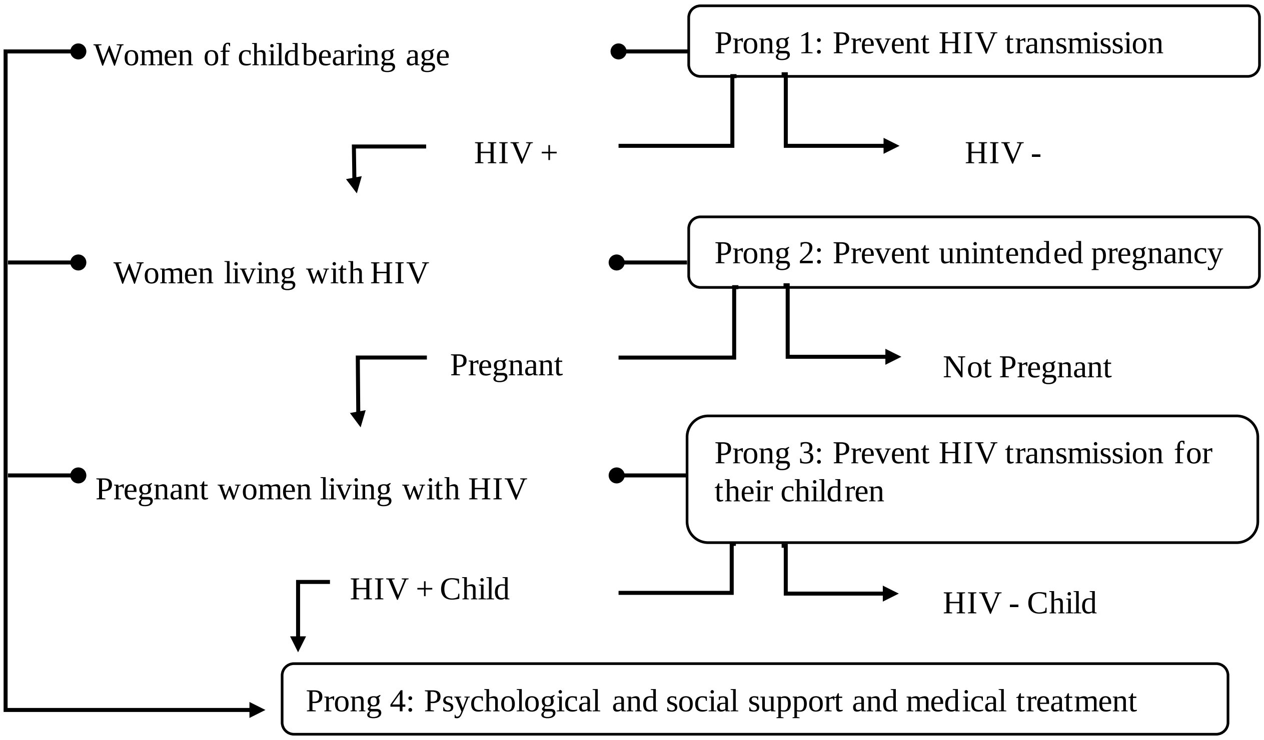


Figure 3.2: A comprehensive HIV-PMTCT

Source: MoH (2015, p. 11)

Note. + indicates positive, - indicates negative

Prong 1: Prevention of HIV among women of reproductive age

The first prong of the strategy focuses on a primary level of HIV prevention among reproductive aged couples, pregnant women, and their husbands. Health intervention programmes include communication, information, and education on HIV and sexual and reproductive health, socio-psychological support for high-risk women to undertake HIV testing, and the provision of social support and treatment for HIV-positive women and their partners (MoH, 2015).

The ABCDE principle is widely promoted in Indonesia. ABCDE stands for: A (Abstinence); B (Be faithful); C (Condom); D (no Drug); and E (Education) (see Figure 3.3). The poster explains “one way to avoid HIV/AIDS is by being faithful to family” and provides additional information about ABCDE. However, with the double standard between the genders (see Chapter 2), and low use of condoms, this approach is not effective for preventing HIV among women if only one partner follows the ABCDE rules (see Higgins et al., 2010). Additionally, the failures of promoting condom use in the general population in Indonesia may relate to narrow response to HIV in Indonesia (such as, HIV is only infected to IDUs, MSM or female sekx workers) and its failure to adequately promote condom use, only limited to among key populations (Marbun, 2013; Praptoraharjo et al., 2016).

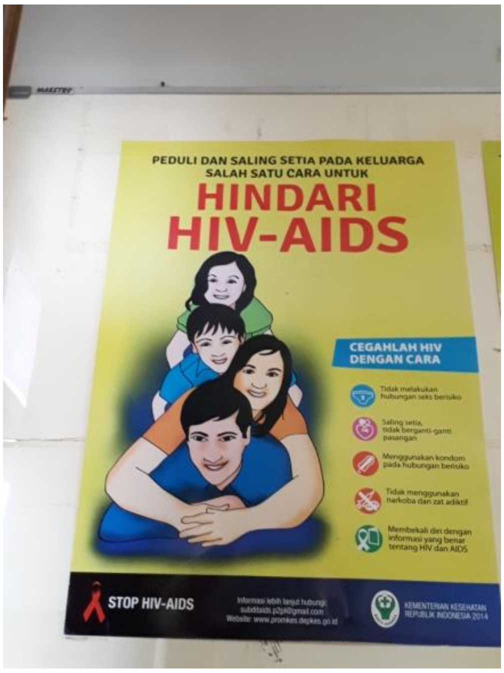


Figure 3.3: Health poster

Note. Reprinted from *Avoiding HIV-AIDS* by Ministry of Health, Indonesia, 2014, Jakarta, Indonesia. Copyright 2014 by MoH.

Prong 2: Preventing unintended pregnancies among HIV-positive women

The second-prong strategy focuses on a secondary level of prevention for HIV positive women in relation to unintended pregnancies. The programmes of this prong include family planning services, counselling, and support for HIV positive women and their sexual partners/husbands. Furthermore, the PMTCT team can be consulted for pregnancy plans if a spouse, or discordant spouse (i.e. a spouse with a different HIV status to his wife), has an undetectable viral load or CD4 over 350 cell/mm^3 (MoH, 2015b). A CD4 (cluster of differentiation 4) count[48] is a test measuring immunity by counting how many CD4 cells are in the white blood cells.

There are choices of contraceptive methods for HIV-positive women and their spouse, HIV-positive or not (Table *3.3*). Condoms are also considered the most effective protection against

---

[48] CD4 cells are those which help combat disease and infection. A healthy person has between 500 and 1400 CD4 cells per cubic millimetre of blood. A CD4 count below 200 indicates serious immune system damage, and means that a person has developed AIDS, the end stage of HIV, and will likely die without treatment.

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 contrapetion		
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.

PMTCT services and gendered stigmatisation of women with HIV (see section on cultural barriers), women may get rejected by family planning services if they disclose their HIV status (IPPI 2017b; Najmah, Davies, & Andajani, 2019; O'Reilly, Kennedy, Fonner, & Sweat, 2013).

Prong 3: Preventing HIV transmission from a HIV-positive woman to her unborn baby

The third prong of the strategy aims to the eliminate perinatal HIV risk. Prong 3 has been the main focus of PMTCT programmes, not just globally but also in Indonesia. Ideally, PMTCT services such as antenatal HIV testing and ARV therapy, should be integrated within antenatal care services. However, not all PMTCT services in Indonesia are integrated with maternal and child health services across all 34 provinces (see Badriah, 2018; Dermartoto et al., 2016; and Lumbantorun et al., 2018). In practice, when a woman is found to be HIV positive, she is referred to a tertiary referral hospital that provides comprehensive PMTCT services such as ARV therapy, safe childbirth, and prophylaxis therapy for babies born to HIV-positive mothers

In terms of safe delivery practice, the literature suggests that caesarean section is still the safest delivery mode for HIV-positive women (De Cock et al., 2000; Hidayana & Tenni, 2015; Imelda, 2011; MoH, 2015b; WHO, 2019b). However, if a woman has taken ARV therapy for approximately six months, or her viral load is less than 1,000 copy/mm^3 at 36 weeks of pregnancy, natural or vaginal delivery is recommended, as it has the benefits of a shorter recovery (MoH, 2015b). Further barriers to accessing PMTCT services in Indonesia are discussed in the last section of this chapter.

Prong 4: Providing appropriate treatment, care, and support to mothers living with HIV, and their children and families

Prong 4 focuses on treatment and support for mothers and their children with HIV. Newborn babies from HIV-positive mothers are required by PMTCT services, to undergo appropriate prophylaxis treatment and feeding practices, have their babies tested for HIV, and access other related postnatal services. Early HIV diagnosis in babies (4-6 weeks after birth) requires a virology test[50] (Polymerase Chain Reaction [PCR] test). It is the most effective HIV test, with

---

[50] PCR tests are expensive (over Rp1,000,000 or NZ$960) and not available in many Indonesian provinces, including South Sumatra. PCR tests are only available in four national referral hospitals in the big provinces: Darmais Hospital in Jakarta, Hasan Sadikin Hospital in Bandung (West Java), Soetomo Hospital in Surabaya, and the Main Medical Laboratory Centre (*Balai Besar Laboratorium Kesehatan*) in Papua (HIV manager in the PHO in South Sumatra, personal communication, 2017).

a repeated test after 4-6 months (MoH, 2015). If the baby is HIV positive, the ARV treatment must be started straight away. When a PCR test is not available, a baby born to an HIV-positive mother should be given HIV prevention treatment within the first 72 hours of the baby's birth, and continue this for 12 to 18 months. Follow-up tests, such as a serology test (rapid test or Elisa test), are conducted in a VCT centre when the baby turns 12 and 18 months respectively (MoH, 2014b, 2015a).

In terms of feeding practice for babies born to HIV-positive mothers, there are two options: 1) exclusive breastfeeding for the first six months, but with a five percent risk of HIV transmission to babies through breastfeeding; and 2) formula feeding with no risk of HIV transmission. Exclusive breastfeeding is recommended as the best practice for an infant's health, as suggested by the WHO and MoH regulation (or *Permenkes* number 36) of 2009 as well as cultural and religious norms (Baintung, 2016). There are some specific requirements for mothers with life-long ARV adherence, high CD4 levels or undetectable viral load, who choose to breastfeed exclusively. These include the use of condoms as a contraceptive method to prevent unintended pregnancy, and ensuring babies take ARV prophylaxis therapy during the period of breastfeeding (IPPI, 2017b; MoH, 2015b).

In practice, formula feeding is the preferred recommendation for babies in an Indonesian family when the mother is HIV-positive (Demartoto, Zunariyah, & Bellarminus Soemanto, 2016; MoH, 2015b) as well as in a global context (WHO & UNICEF, 2016). However, formula feeding requires family and society members accepting the mother's decision not to give breastmilk to her baby. Formula feeding also needs to consider whether the family can afford to buy formula milk. Parents have to be able to prepare and give formula milk safely to their children, and ensure adequate continuity of the availability of formula milk. These requirements are known as AFASS (Acceptable, Feasible, Affordable, Sustainable, and Safe) (IPPI 2017a; MoH, 2015b).

Ministry of Health Regulations 2013-2017

This section overviews government regulations supporting PMTCT services in Indonesia. The Ministry of Health or MoH, as the top level in the Indonesian Government in relation to public health, has the function of managing public health programmes, which includes the publishing of regulations to support PMTCT (Mahendradhata et al., 2017). Between 2013 and 2017, the Indonesian MoH introduced at least eight regulations to support the implementation of PMTCT and its effective coverage in Indonesia. The central and local governments, across Indonesia, 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 epidemic[51] (as in Papua), and a concentrated HIV epidemic[52] (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

and specialists, can also initiate tests and counselling, named provider-initiated testing and counselling (PITC) (*Permenkes* no. 74 [2014], Article 3, point 2). If the results show HIV positive, a pregnant woman is required to be referred to a *puskesmas* that provides further HIV tests to reconfirm the HIV result, before being referred to PMTCT services (based on *Permenkes* no. 51 in 2013), followed by HIV treatment. With the current regulation, *Permenkes* No. 52 in 2017, the central government highlighted the importance of HIV, syphilis, and Hepatitis B tests during pregnancy, through PMTCT services. The implementation of these programmes of PMTCT services focusing on HIV, syphilis and Hepatitis B tests was an on-going process during my fieldwork.

The foregoing regulations provide over-arching policy laws regarding PMTCT services. However, a set of regulations does not necessarily indicate effective implementation of comprehensive PMTCT services in the 34 provinces in Indonesia. The disparities of interregional level, such as the quality of human resources, budget sharing, and harmonisation of programme planning and implementation may result in different achievement levels in different provinces, including decision-making processes and policy implementation (Mahendradhata et al., 2017; WHO & MoH, 2017). For example, HIV screening of pregnant women in Palembang was first introduced in 2017, in *puskesmas* with VCT centres, even though the central government had passed the regulation to mandate tests for HIV for all pregnant women in the wider population in 2013 (*Permenkes* no 51 in 2013). Arguably, the implementation of policies depends on key players in the HIV programme services and funding bodies, which may impact on the implementation of management strategies in PMTCT services.

Key players of PMTCT

This section explains primary key players of PMTCT programmes in Indonesia. There are many key players in HIV programmes such as PMTCT services. The main players are: 1) Government of Indonesia; 2) NGOs related to HIV; and 3) International donors. The MoH and PHO, the key players within the Government of Indonesia, focus on Prongs 3 and 4—HIV testing, biomedical therapy, and other medical treatments. NGOs tend to focus on all four prongs, but mainly target key populations with donor-based projects with international organisations.

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 system [53] (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 Penyelenggaara 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 betweeen 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 month[54] 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

HIV-focused non-governmental organisations

The second sub-section of key players in relation to PMTCT are the NGOs. These have become integral players in the HIV programmes in Indonesia and represent PLWHIV (Praptoraharjo et al., 2016a). HIV-focused NGOs mainly focus on prevention and support programmes for key populations related to HIV, such as PMTCT programmes in relation to prongs 1, 2, and 4. Most NGOs, however, have fragmented roles among key populations. These roles include engaging those in key populations to access HIV testing, providing condoms for high risk groups, and focusing on psychosocial support for women and children living with HIV (Praptoraharjo et al., 2016a; Suharni et al., 2016). The majority of NGOs also depend on international funding for their programmes. This might compromise other Indonesian agencies, including the MoH and PHO, as their data, statistics, monitoring and evaluation are not necessarily transparent (Praptoraharjo et al., 2016a; Suharni et al., 2016). For example, during my fieldwork, I found NGO workers did not always provide accurate data to the PHO, so the PHO was providing services based on inaccurate information.

There are some national NGOs, such as the HIV-positive women association IPPI, Lamp of Knowledge Organisation (*Yayasan Pelita Ilmu*) and Spritia Organisation (*Yayasan Spiritia),* and local NGOs in the provinces. For example, in Jakarta, a seropositive women support group, called *TOP* (the Indonesian word for “great”) support, provides support people to accompany HIV-pregnant women accessing PMTCT services (Imelda, 2011, 2014). Figure *3.4* is an example of an IPPI project outcome, in which the Global Fund and MoH worked with NGOs to disseminate information related to PMTCT services to the provinces (IPPI 2017a). The next part of this section describes in greater detail the role of international donors that support HIV programmes in Indonesia.

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 and technical assistance for STI and HIV services in Jakarta, West Java, Central Java, Bali and North Sulawesi, during the same period (2008-2015) (see Praptoraharjo et al, 2016a, p. 91-92).

The Global Fund has a major role in providing ARV and HIV training for health workers related to HIV services and care, including that provided by PMTCT services. Between 2009 and 2014, The Global Fund focused on 12 provinces in 2010, increasing to 21 provinces in 2015 (Praptoraharjo et al., 2016a). Recently, the Global Fund offered a new funding model for Indonesia to improve universal coverage of HIV prevention and treatment, including the provision of ARV drugs for PLWHIV, including HIV-positive pregnant women (The Global Fund, 2018). The uniqueness of the Global Fund is that it has committed to increasing ownership of long-term HIV programmes in Indonesian’s health system by developing a Country Coordinating Mechanism (CCM) (Praptoraharjo et al., 2016a). Nevertheless, about 50% of funding for HIV programmes in Indonesia is from the GFATM (a part of the IATT), a key player over the last decade in the provision of PMTCT services (Suharni et al., 2016). In light of the roles of these funding agencies, it is not surprising that Indonesia’s PMTCT targets and directions are strongly influenced by international-donor targets, who must make regular reports to the international funding agencies.

In summary, there are key players delivering their own response to the WHO’s four pronged strategies of PMTCT programmes. A proliferation of international donors still dominates the HIV programmes supported by NGOs and the MoH. Nevertheless, PMTCT programmes in Indonesia, like those globally, have been dominated by the need to prevent vertical HIV transmission from mother-to-child (Prong 3). However, the focus of other prongs has been limited, and implementation of Prong 3 strategies has been slow, and with limited success.

Services coverage, however, is still low. Figure 3.5 shows that only seven to eight percent of all pregnant WLWH who required PMTCT services were reached between 2011 and 2016 (an estimated 18,872 and 19,636 pregnant WLWH in 2015 and 2016 respectively) (MoH, 2013a, 2013c). However, only 1,528 and 1,688 pregnant WLWH accessed PMTCT services annually in 2015 and 2016, yielding a high risk of vertical transmission from HIV-positive mothers to their unborn children (MoH, 2013a, 2013c). An investigation of the barriers to access is therefore needed to understand why the accessibility of PMTCT programmes is still below 10 % of all HIV-positive pregnant women, resulting in an estimated 3,000 newly infected-HIV children (0-14 years) annually between 2015 and 2017 (World Bank, 2019).

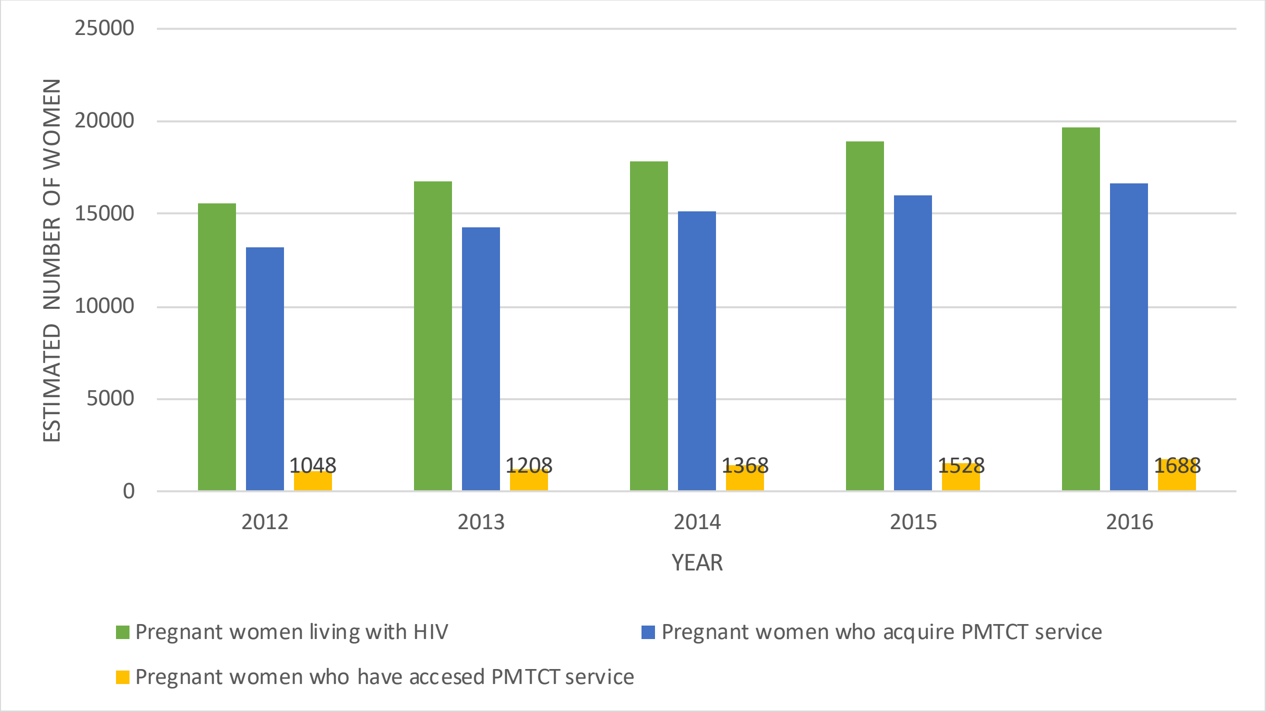


Figure 3.5: The gap between the need of PMTCT services (blue) and accessibility of PMTCT services for pregnant women living with HIV (yellow)

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).

The first key health system barrier to be discussed is that of inadequate antenatal HIV testing. The first step for pregnant women accessing PMTCT services in Indonesia is to seek an HIV test, nevertheless, HIV screening is available mostly at primary health services, such as *puskesmas* and limited hospitals. Nevertheless, only about 16.6% of pregnant women in Indonesia make antenatal visits to *puskesmas, and* 10% make visits to hospitals (MoH, 2013e). About 55% of all mothers go to private midwives (MoH, 2013e) who do not offer onsite HIV testing (Wulandari et al., 2019). As a result, private midwives need to refer pregnant clients to the closest *puskesmas* or hospital that offers HIV testing (MoH, 2014). Within Indonesia's fragmented health system, a private midwife referral depends on multiple factors, including the agreement of the PHO, *puskesmas*, and midwifery organisation, and the midwife's understanding of and training in relation to PMTCT services (Demartoto et al., 2016; Wulandari et al., 2019). According to Liem and Adiyanti (2013), Waluyo et al. (2015) and Lubis, Wulandari, Suariyani, Adhi, and Andajani (2019), midwives' negative attitudes towards HIV, or fears of being rejected by pregnant women, may contribute to their reluctance to introduce HIV testing to their clients.

A second key health system barrier is the bureaucracy surrounding referral systems for accessing PMTCT services. As discussed previously, the health system in Indonesia is complex with a fragmented bureaucracy, evidenced by a lack of integration between healthcare providers at district and regional or provincial level. An HIV-positive pregnant woman needs a tertiary or provincial level referral before she can access ARV therapy and prepare for safe labour and pregnancy, and such a referral is generally only available in the capital city or region of each province, unless in an emergency situation. However, this referral system may not work for those in need of health services and women (particularly those in rural areas) can incur indirect costs associated with the referral (e.g. transportation cost) (Badriah et al., 2018; Hardon et al., 2009; Hidayana & Tenni, 2015; Wulandari et al., 2019). Arguably, health workers at tertiary referral hospitals cannot monitor a woman in need of PMTCT services from other primary or secondary referral health-care providers because of unintegrated health system information held by healthcare providers (see Figure *3.6*). There is a common assumption that the lack of accessibility to PMTCT services is due to women's own self-stigmatisation of being WLWH, and not the real reason, which is the prohibitive red-tape in the referral system.

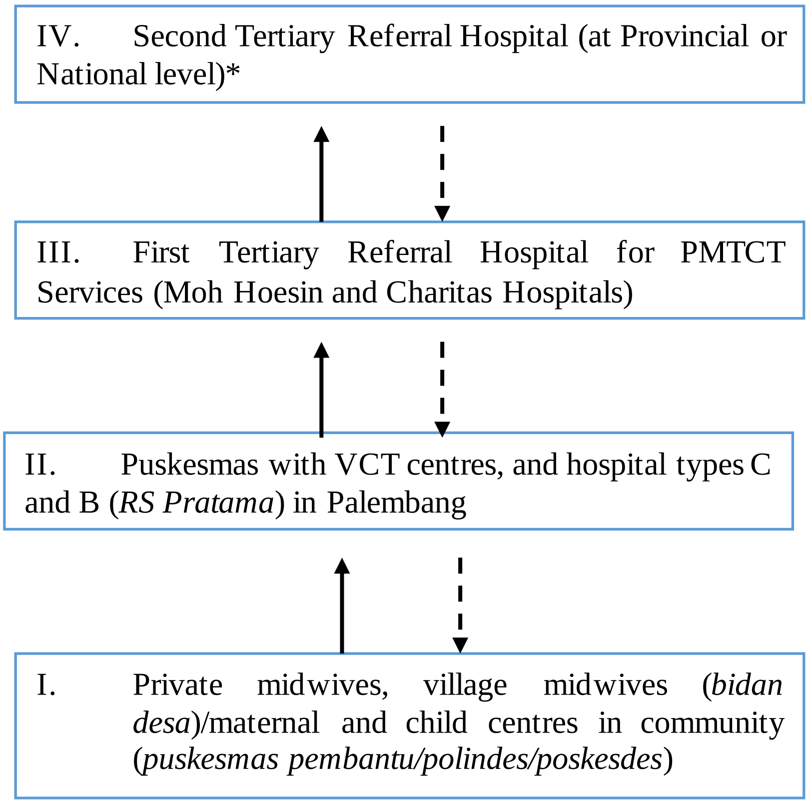


Figure 3.6: Referral system of the four pronged-strategy in PMTCT services in South Sumatra, Indonesia.

- - - - → 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

HIV status to their partners/husbands (Anindita & Shaluhiyah, 2016; Badriah et al., 2018; Oktavia, Alban, & Zwanikken 2012).

Economic barriers

HIV testing and the provision of ARV is free, provided a woman is enrolled with public insurance. However, as noted previously, given the difficulties accessing universal social health insurance, not all Indonesian women are able to enrol. Women face two main economic barriers in accessing PMTCT services: (1) the women are often poor and unable to enrol in free public insurance; and (2) the health system disadvantages poor people by not covering the indirect costs they incur when trying to access PMTCT services at tertiary referral hospitals.

Poverty is a primary economic barrier to accessing PMTCT services, because without enrolment in public insurance, WLWH from poor families may not able to access PMTCT services. Among HIV-positive pregnant women from poor families, Demartoto et al. (2016) found limited enrolment in public insurance, which may have prevented women from accessing PMTCT services. caesarean delivery, the main option of safe labour delivery for HIV-positive mothers, is expensive, and the in-patient room for post-delivery recovery also requires payment. The minimum payment for a caesarean delivery is approximately $ 1500 NZD, compared to that for a normal delivery, which is approximately $ 30 NZD (Primastika, 2019). In addition, formula milk, the main feeding recommendation for babies born to HIV-positive mothers, may be an additional economic burden (Dermartoto et al., 2016).

The second economic barrier is the bureaucratic nature of Indonesia's health service, which severely disadvantages poor women. Indirect costs such as transportation and loss of earnings due to long-waiting times and red-tape involved in referrals, are additional economic barriers (Badriah et al., 2018; Lumbantoruan et al., 2018; Riyarto et al., 2010). Although ARV and prophylaxis treatments are free, these services are still generally only available at district and provincial level (Badriah et al., 2018; Hidayana & Tenni, 2012; Lumbantoruan et al., 2018), making them difficult to access. In addition, antenatal HIV testing is only available in a few *puskesmas* and NGOs and antenatal care services (including caesarean sections) requires with enrolment in public insurance (BPJS). In Palembang, South Sumatra, testing has been available in all *puskesmas* only since 2017; while in Jakarta, Indonesian's capital city, antenatal HIV testing for pregnant women was initiated by the NGO *Yayasan Pelita Ilmu* a decade ago (Imelda, 2011). Therefore, costs may be an added burden for women economically dependent on their husbands, and contribute to fewer newly HIV-positive (pregnant) women able to enact their rights to raise HIV-free infants (Badriah et al., 2018; Lumbantoruan et al., 2018).

Information barriers

Inadequate access to information may prevent women from making informed choices regarding the best decision. Lack of information comes in the form of (1) no information being available; (2) a lack of well-trained counsellors; and (3) not knowing where to find information.

The first key information barrier to be discussed is that some women do not know about PMTCT services, and therefore do not attempt to access them. Evidence shows a lack of health services promotion at community level regarding PMTCT services; the information is available on request only (Badriah et al., 2018). HIV-positive women may have limited knowledge of PMTCT services, even after exposure to health services (see section information barriers at global context).

A second key information barrier is caused by the lack of well-trained counsellors with high-quality HIV-education, and a general lack of understanding about gender discrimination and women's rights to raise HIV-free children (Butt, 2011; Butt, Munro, & Numbery, 2017; Hardon et al., 2009; Oktavia et al., 2012). Furthermore, women may not receive correct information before or after being tested for HIV, potentially resulting in the denial of their HIV status (Imelda, 2014), difficulty accessing ARV therapy (Lumbantoruan et al., 2018), and the late initiation of ARV therapy among pregnant HIV-infected women (Oktavia et al., 2012).

A third key information barrier is that women may not know where to look for information. Women who are exposed to peer support from PLWHIV and well-trained counsellors are more likely to obtain correct information on how and where to access PMTCT services (Hidayana & Tenni, 2015; IPPI 2017b; Lumbantoruan et al., 2018). Arguably, not all PLWHIV want to visit an NGO to seek information and help accessing HIV treatment, because of confidentiality concerns (Hidayana & Tenni, 2015; Nugroho et al., 2018), and because not all WLWH are not exposed to well-trained counsellors during their visits to healthcare providers (see Butt, 2011, 2015).

In summary, the interplay of information barriers, such as inadequate knowledge and experience related to accessing PMTCT services, may contribute to poor negotiation and interaction with healthcare providers in order to exercise women's rights to have HIV-free children in Indonesia. Consequently, many women may fail to seek and/or obtain important information about PMTCT services (Busza et al., 2012; Gourlay et al., 2013; Hlartaithe et al., 2014; Turan & Nyblade, 2013).

Barriers caused by gender discrimination

Cultural barriers add another layer of complexity in understanding the barriers for women accessing PMTCT services. The accessibility of PMTCT services needs to be considered in the context of women’s perspectives, gender construction, and the diverse cultural settings in Indonesian society. Indonesian women face gender discrimination due to a double standard that is applied to men and women, reinforced by cultural and religious values, resulting in barriers against making informed choices and accessing PMTCT services.

Women face two main cultural barriers linked to gender discrimination. The first cultural barrier is a form of gender discrimination. This means women may be denied their right to access PMTCT services. The second barrier is related to health workers who reinforce societal gender discrimination, thereby compromising women’s rights and curtailing their access to PMTCT services.

It is common for women to internalise gender discrimination. Gender discrimination may manifest as women feeling ashamed, immoral, or even unworthy to visit healthcare services (Butt, 2011, 2015; Butt et al., 2017; Damar, 2014; Damar & du Plessis, 2010; Imelda, 2011, 2014). Women may blame themselves for their HIV-positive status, or even not accept their HIV status, thus, limiting planning around their pregnancy and access to full and comprehensive PMTCT services, and their willingness to disclose their HIV status to their partners (Anindita et al. year; Butt, 2015; Damar, 2011; Hidayana, 2012; Imelda, 2015). Furthermore, women exposed to the virus from their HIV-positive husbands, may require permission from their husbands to access HIV testing, and also lack the power to refuse unsafe sex (Butt, 2015; Lumbantoruan et al., 2018).

The lack of understanding about HIV and gender discrimination, and the institutionalised stigmatisation surrounding HIV is evident in the Indonesian health setting, even among HIV specialists (see Bennett, 2015; Najmah et al, 2019). As noted in the section addressing information barriers in the Indonesian and global context, there are insufficient adequately trained personnel with an understanding of gender discrimination and women’s rights, to ensure access to health services when dealing with HIV clients. This ignorance of health workers' professional requirements to uphold the rights of HIV infected women to access PMTCT services, may result in a lack of dissemination of sufficient and relevant HIV awareness information (Badriah et al., 2018). Thus, gendered discrimination can result in unprofessionalism among health workers, who may be afraid to treat HIV-positive women or avoid treating them altogether, violating clients' rights to access appropriate PMTCT services.

In conclusion, gendered cultural barriers must be recognised as an important factor in obstructing access to PMTCT services. Stigmatisation and gendered discrimination, along with structural, economic, and information barriers, may prevent women from accessing PMTCT services. Women's and men's status within a family may reinforce gendered morality and discrimination for HIV-positive women, making it difficult for them to access PMTCT services. Unfortunately, women may not necessarily be aware that they are being discriminated against, and perpetuate the same cultural norms that violate their rights to making informed choices, accessing prevention and treatment services, and having the opportunity to bear healthy HIV-free babies.

4. Summary of PMTCT in global and Indonesian contexts

There has been much work done on improving access to PMTCT services, but there are still many shortcomings, including a lack of focus on women's needs, poor consideration of the cultural context in Indonesia, and donor-driven agendas. The increasing number of HIV-positive children born to HIV-positive mothers is still a serious concern, despite the increased coverage of PMTCT services. This chapter has shown the importance of my research on enabling HIV-positive women to access PMTCT, by addressing barriers based on HIV-positive women's aspirations in both global and Indonesian contexts. I argue that PMTCT programmes are simplistic. Biomedical prevention approaches for early diagnosis and ARV therapies for pregnant women to eliminate vertical transmission of HIV do not accommodate the multi-layered, complex socio-cultural and political context of women's lives and the ability of developing countries with limited health resources to enhance PMTCT coverage, particularly in Indonesia, the study context.

By inviting women as the experts in their life experiences, to be creative agents of change, results from this study will provide insights into women's involvement as change agents in PMTCT services both in the Indonesian context and in other countries of similar context. Solutions that come from HIV positive women themselves would be relevant to the lives of other HIV positive women, who also experience stigma and discrimination. Further explanation of the methodology will be discussed in the fourth Chapter.

Chapter 4. Methodology

> I kept trying to persuade my supervisors that I should use a mixed methodology. Sharyn said it was possible, but Sari said to focus on one approach only as we had a limited time. She said to focus on a qualitative approach. Honestly, at the first stage of my PhD, I was a bit disappointed, but I started to reflect on the benefits of my own journey using a qualitative approach under their intensive supervision. I learned the importance of ownership of the research process for my participants and me. It was challenging, but this process was eye opening for me as a public health researcher working in a positivism paradigm.
>
> I am Najmah–a positivist researcher (an epidemiologist and statistician) and now a novice practitioner of feminist and participatory action research. (Najmah, Research Journal, 2017)

In this methodology chapter, I outline the thinking behind my decision to use FPAR as the methodological framework for my study and the implementation of FPAR during my fieldwork. This chapter is divided into six main sections: 1) Research paradigm; 2) Pre-fieldwork; 3) Fieldwork-study design; 4) Creating space with HIV-positive women and dissemination process; 5) Ethics and protection participants; and 6) Data analysis. I start with an overview of the research paradigm: the research epistemology, research methods, and data collection.

1. Research paradigm

A research paradigm is an interpretative framework that is informed by a set of beliefs about the world and how the world should be studied (Denzin & Lincoln, 2005; Kuhn, 2012). In this study, I have organised my research paradigm according to my epistemology, theoretical framework, methodology, and method[55]. This chapter includes three main sections. First, I

---

[55] Crotty (1998), Denzin and Lincoln (2008) and Saunders, Lewis, and Thornhill (2012) discussed the major dimensions of a research paradigm as including ontology, epistemology, theoretical framework, and methodology. Ontology is concerned with the nature of reality and the nature of the human being in real life. Epistemology is a branch of philosophy that studies the nature of relationships that exist between researchers and research participants, and how their relationship is understood (Crotty, 1998). Between epistemology and methodology, Crotty added the theoretical perspective - the research philosophical position informing the methodology and context of the research process. Finally, the methodology is often explained as the overall guiding principles of how the researcher gains knowledge of the research topic, and the methods, research tools, and techniques used to obtain that knowledge (Crotty, 1998; Denzin & Lincoln, 2005; Saunders et al., 2012).

discuss my research paradigm, including the feminist research epistemology and empowerment in feminist research as my theoretical framework. In the second section, I present FPAR as my methodology, and the third section overviews the research method.

Feminist epistemology

I chose feminism as my epistemological stance[56]. Diverse perspectives, epistemologies, and critiques exist under the umbrella of feminist research (Harding, 1987; Lykke, 2010; Reinharz, 1992). In general, feminist research is interested in the examination of change in basic structures of oppression and the reduction of injustice to women, and seeks deeper understandings of the hopes, aspirations, and lives of women grappling with societal impositions and injustice (Crotty, 1998; Hesse-Biber, 2012). Women are believed to be resourceful and resilient, have their own voices and expertise, and able to promote informed change relevant to their life context and health (Ponic et al., 2010). Common positions of feminist epistemology inform the current research. The next section discusses three points related to feminist research: 1) the plurality of women's unique experiences, 2) feminist research relating to women's empowerment, and 3) the importance of reflexivity in feminist research.

Firstly, feminist research is open to the plurality of women's lived experiences (Doucet, 2007; Lykke, 2010). This research recognises the unique experiences of every HIV-positive woman and her contribution to knowledge (see Doucet, 2006). Unfortunately, knowledge of women's social reality and life, according to Harding (1987) and Hesse-Biber and Leavy (2010), is often viewed in a biased way in terms of gender and androcentrism, both by researchers and their research subjects. Androcentric research tends to focus on deductive conclusions, objectivity, male perspectives, and patriarchy, and does not consider that the male experience is different from the female experience (Handayani & Sugiarti, 2002). Following Harding's argument, the

---

[56] "Feminist epistemology mirrors the diversity of epistemology generally, as well as the diversity of theoretical positions that constitute the fields of gender studies, women's studies, and feminist theory. An emphasis on the epistemic salience of gender and the use of gender as an analytic category in discussions, criticisms, and reconstructions of epistemic practices, norms, and ideals is common to feminist epistemologies. While a feminist epistemology is not easily and simply characterised, feminist approaches to epistemology tend to share an emphasis on the ways in which knowers are particular and concrete, rather than abstract and universalizable." (Internet Encyclopedia of Philosophy, A peer-reviewed academic resource, *https://www.iep.utm.edu/fem-epis/*)

current research puts women's informed social, cultural, and political context as central to the research process and advocacy for HIV prevention and PMTCT access.

Secondly, feminist research seeks to contribute to women's empowerment (Hesse-Biber, 2012). Women have the potential to contribute to the development of collective consciousness through their active participation, shared knowledge, and collaboration in the research itself (Crotty, 1998; Lykke, 2010). Women, the subalterns, are often "bearers of a privileged access to potentially transformative insight into the existing hegemonic gender orders" (Harding, 1993, p. 130, as cited in Lykke, 2010). The work of Kramarae and Spender (1992) further supported the notion that women have knowledge of and insight into their social life circumstances, that enables them to transform themselves through knowledge construction. In relation to health policy, this research sharpens critique on the diverse experience of women's health and social inequalities in research and policy on HIV-positive mothers and PMTCT services (Weber & Castellow, 2012).

Thirdly, feminist research recognises unequal power relations between participants and researchers (Crotty, 1998; Lykke, 2010); hence, according to Burns and Chantler (2011), "the ongoing questioning of one's place and power relations within the research process or reflexivity" (p. 22) is a major concern in this research. Because of the power relation, my role as a researcher had to be continuously checked to identify the degree to which my position influenced respondent participation or if a participant's position impacted on other participant's freedom to share his or her experience in my study (Kramarae & Spender, 1992). In addition, I needed to be aware of the research processes, such as the inclusion or exclusion of particular participants, identification of the appropriate methods for different circumstances, their influence of my experience in the field on the data analysis, and my critical positioning as a researcher (Rae & Green, 2016). Subjectivity is an integral component of feminist research, and my self-awareness in terms of being objective, neutral, and value-free in conducting research was a challenge (see Burns & Chantler, 2011).

In summary, feminism is underpinned by the philosophical belief that women are the real experts on women's problems and solutions. This study assumes that HIV-positive women in Indonesia are living in social settings, institutions, and cultures that are marginalised and overshadowed by other dominant, groups (e.g. men, HIV policy makers, or health workers). As such, their voices and concerns may have not been fully heard. Hence, the active inclusion of women's expertise is one approach to gain relevant and first-hand knowledge of existing 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.

Feminist Participatory Action Research (FPAR)

As noted, this research focuses on social processes and collaboration in research, and has similar principles and assumptions to feminist social movement research and scholarship (for example, emancipatory and transformative intentions). This research endeavours to create a safe space for HIV-positive mothers to be involved in the process of making a commitment to participate in research activity, breaking the silence of their voices and sharing their lived experiences, sharing knowledge on an issue or problem, building interpersonal relationships, and raising political awareness in order to create solutions together. This section elaborates on the relevance of FPAR in my study and the impact it had on the richness of the data collected.

FPAR, first introduced by Patricia Maguire (1987), and used by Brinton Lykes (2007), Collen Reid, and Wendy Frisby (2008), was chosen as a suitable research methodology to facilitate the emergence of women's voices and collective empowerment leading to social action. A critique of Participatory Action Research (PAR), in practice and theory, is that gender oppression and female concerns are not addressed (Maguire, 1996; Mclntyre, 2008; Ryan-flood, Roisin, & Rosalind, 2010). However, Reid and Frisby (2008) argued that feminist researchers and PAR researchers can work together on research that focuses on critical principles countering gendered, racialised and class ideologies, and on the unequal power relationships that enhanced the democratisation of the research process. I provide evidence this collaboration contributed to social justice and was an essential part of my research process (see Chapter 8).

Maguire (1987) implicitly introduced the principles of FPAR in her book "*Doing participatory research: A feminist approach*," followed by her paper "*Considering more feminist participatory research: What's congruency got to do with it*" and a book chapter, "*Uneven ground: Feminism and action research*" (Maguire, 1987, 1996, 2006). She described her first experience with FPAR in a project with Native American women who were survivors of sexual abuse and highlighted how building trust was an important stage in this research. Maguire (1996) introduced further considerations for FPAR, such as creating meaningful participation for women throughout the research process, and outcomes that included a collective critical consciousness that challenges the oppressive attitudes, beliefs, and practices that are deeply embedded in society. In this study, I use the terms "FPAR" or "feminist PAR" to refer to previous research related to feminist action research, feminist community research, feminist participatory research, and feminist PAR.

Lykes and Coquillon (2007), Lykes and HershBerg (2012), and Reid and Frisby (2008) explicitly introduced the terms Feminist-infused Participatory Action Research. There are three main dimensions of social transformation that allow the necessary place and space to reposition gender, race, and class, to bring about indigenous knowledge and wisdom, and "deploy intersectionality" as an analytical tool for social transformation (Lykes & Hershberg, p. 331). In addition, Reid and Frisby articulated six dimensions of FPAR as further guidelines to help the novice feminist participatory action researcher:

1) centring gender and women's diverse experiences while challenging forms of patriarchy;
2) accounting for intersectionality;
3) honouring voice and difference through the participatory research process;
4) exploring new forms of representation;
5) developing a critical reflection or reflexive dialogue between the researcher and participants; and
6) honouring many forms of action.

As noted point 3 of dimensions of FPAR, it accounts for intersectionality. The intersectionality is a theoretical framework that posits that multiple social categories (e.g. race, ethnicity, gender, sexual orientation, socioeconomic status) intersect at the micro level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g. racism, sexism, heterosexism, see Bowleg, 2012, p. 1267). FPAR offers a promising method for understanding the tensions and privileges of women's voices and aspirations, to accommodate women's problems and provide solutions that intersect with the multi-layered, complex socio-cultural contexts of women's lives. Hence, discussions about women's health need to be beyond frameworks of social determinants of health, ecological studies, and social discrimination or social inequality (Bowleg, 2012).

I argue for the centrality of a woman's position as a subaltern, as a woman, a mother, and an HIV-positive individual. This is followed by co-constructing knowledge and engaging in the co-learning process through women's shared experiences, thoughts, and aspirations. Furthermore, even the often-silenced voices are enabled to develop a collective voice to raise their critical consciousness, and to reflect and find solutions to their problems, leading to individual and collective actions (Brydon-Miller, Maguire, & McIntyre, 2004; Lykes & HershBerg, 2012; Ponic et al., 2010). In women's health, Ponic et al. (2010) added that creating 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; Mclntyre, 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), Ponic 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.

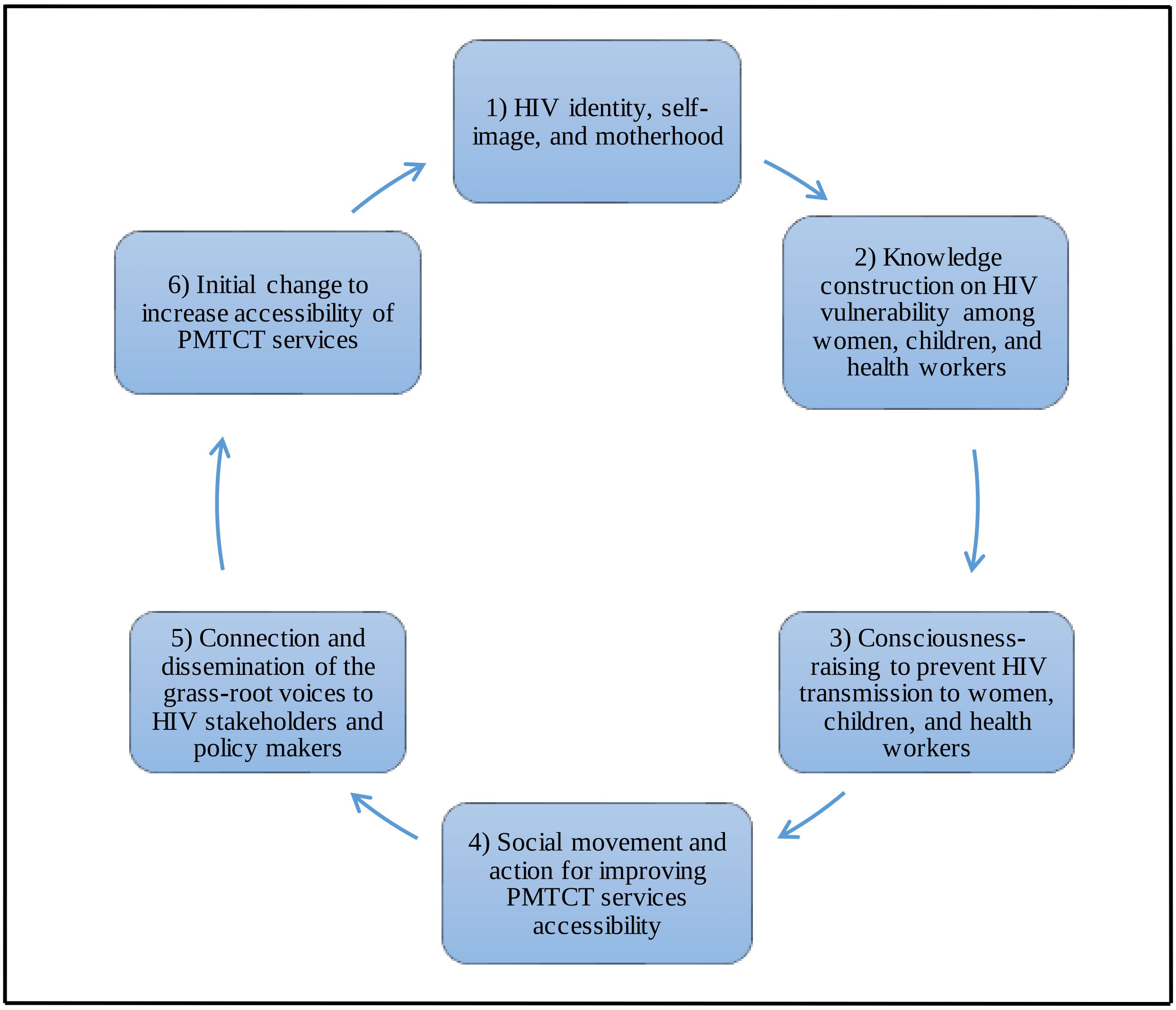


Figure 4.1: FPAR cycle of enabling HIV-positive women to access PMTCT services

Sources: Lykes (2007, 2012); Ponic et al. (2010); Reid & Frisby (2008); Carr (2003).

Previous research in health and social fields has used various methods in applying FPAR, such as discussions or workshops, interviews, narrative stories, and visual methods with women of different races, languages, and ages (e.g. Botha & Hay, 2016; Jategaonkar & Ponic, 2011; Lykes et al., 1999; Yoshihama & Carr, 2002). In addition, these studies emphasised the importance of building trust and creating space among indigenous women, such as the Mayan Ixil Women of Chajul (Lykes et al., 1999), Hmong women in Canada (Yoshihama & Carr, 2002), vulnerable women, such as those fleeing from violence at home (Jategaonkar & Ponic, 2011; Ponic et al., 2010), and adolescent girls from divorced families (Botha & Hay, 2016). As outsiders, the researchers emphasised working with insider groups by giving them training, workshops, or spaces in their own community (e.g. Jategaonkar, & Ponic, 2011; Lykes, 1999; Ponic & Frisby, 2010; Yoshihama & Carr, 2002). The current research, as it was participatory in nature, was open to the use of any data collection method that would enhance women's participation and social transformation.

This section analysed the application of FPAR in this research. I have argued that women's lived experiences, as central to this research, should account for power dynamics and gender inequality, and address the importance of collective work for knowledge construction, advocacy, and dissemination. The next part of this chapter discusses the methods of data collection.

Data collection methods

Methods utilised in the current study included a series of focus group discussions (FGDs), interviews, and visual methods. FGDs were particularly useful in gaining participant ideas and aspirations that might not have been accessible without group interaction (Hennink, 2007; Liamputtong, 2011). Participants were able to discuss and ponder topics with their peers. I, as researcher, was able to examine attitudes, behaviours, or differences in perceptions amongst participants, which would not have been easily observed during individual interviews (see Hennink, 2007; Liamputtong, 2011). Interviews were undertaken in cases where it was a participant's preference over group discussion, and were held over lunch, in their offices, or while accompanying them to their activities. Carpiano (2009) argued informal or 'go-along' interviews in health research provide meaningful insights into participants' personal strengths, capacities, and assets within their networks that allow for the process of empowerment to happen, which might not be easily noticed during a more formal interview process with open-ended questions.

Two interview methods were used: naturalist and constructivist. Naturalist interviews aimed to gain an authentic insight into the lives of HIV-positive mothers (Rubin & Rubin, 2012; Silverman, 2014). During these interviews, I was able to become involved emotionally with respondents and share my empathy. In line with the principle of constructivist interviews, HIV-positive women and I were able to engage with each other to construct meanings from their lived experiences regarding PMTCT access and possible solutions to enhance accessibility of these services. Furthermore, virtual discussions were used as an alternative approach, using applications such as Facebook Messenger or WhatsApp to keep in touch with participants (Pranee Liamputtong, 2011). Individual interviews through private online messaging were used to follow up with some participants to confirm or triangulate information related to individual life experiences, HIV programmes, or PMTCT services.

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).

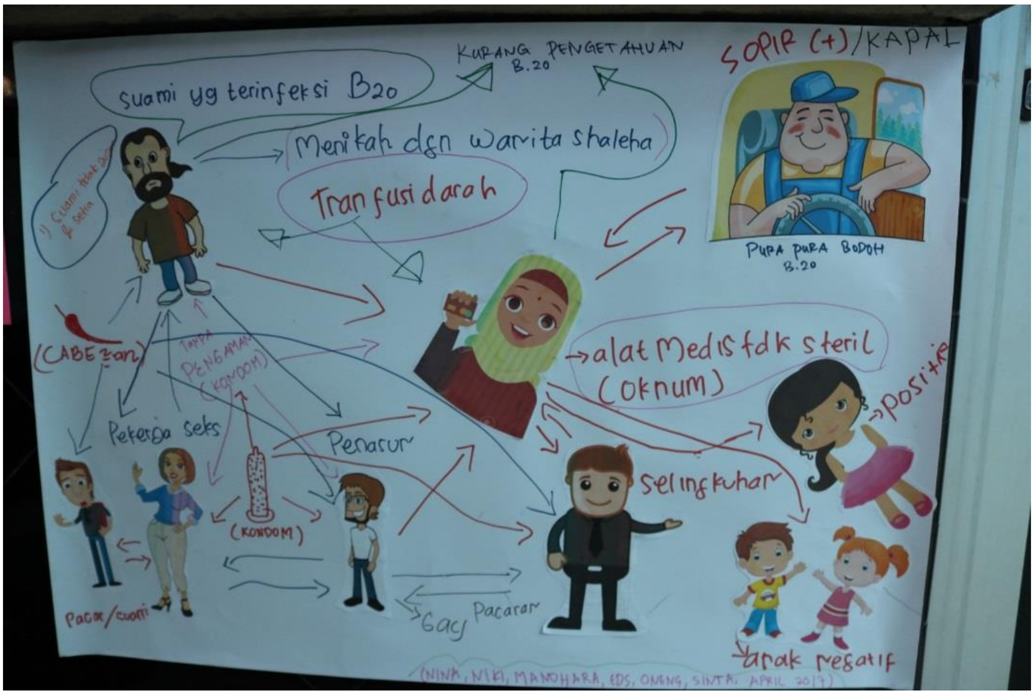


Figure 4.2: A collage showing modes of HIV transmission among women of childbearing age (For explanation of this figure, see Chapter 5)

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

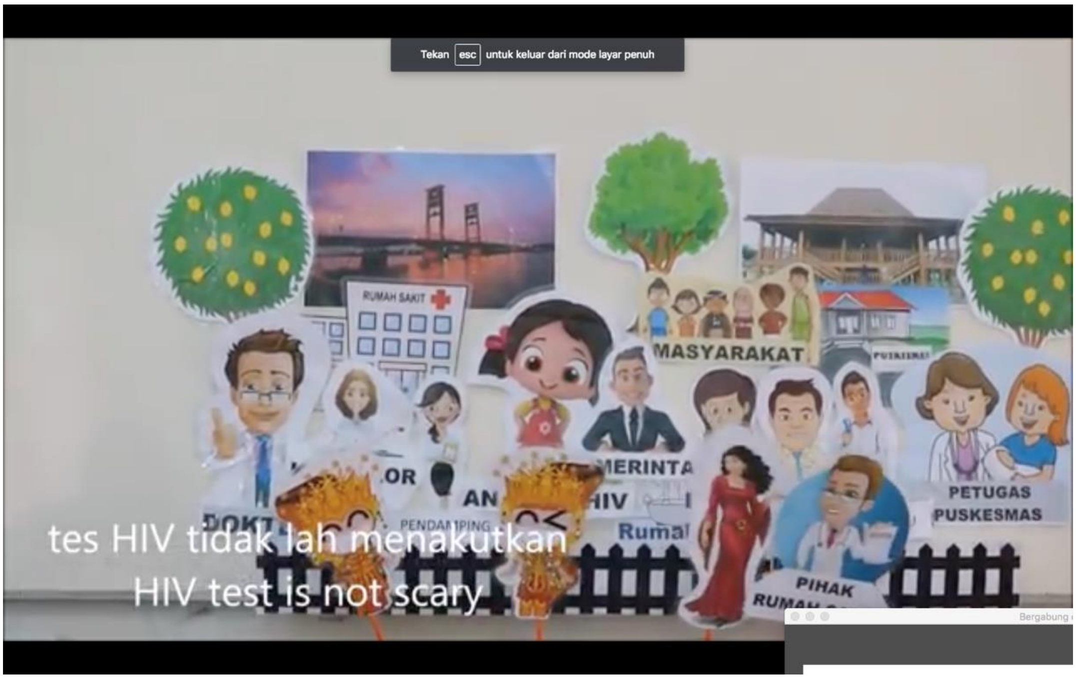


Figure 4.3: Visual outcome: Puppets used for creating a video of an adaptation of a traditional Indonesian song "*Cuk Ma Ilang*[57]" (Palembang Idiom)

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

2. Pre-Fieldwork

This section explains the preparation before conducting my fieldwork. It includes performing pre-fieldwork practice of FGDs and interviews, and my reflections during the pre-fieldwork.

Pre-fieldwork FGD practice

The pre-fieldwork preparation was conducted in Auckland between December 2016 and March 2017. Using the social media application, WhatsApp, I invited Indonesian women of childbearing age to participate in my study. I also invited my Ph.D. colleagues—two Indonesians and one Thai—and my supervisors to undertake mock interviews and discuss my

---

[57] *Cuk Ma Ilang* is originally a traditional Palembangese folksong. The song contains four sentences in each verse and the lyrics in the second verse will be the answer to questions in the first verse. Every second verse starts 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 or melancholic or cheerful and up-beat. Link: https://www.youtube.com/watch?v=APKaNT7SYQ8

fieldwork plan. This pre-fieldwork included two FGD practice sessions and four mock interview sessions. This preparation was important to enhance my ability to maintain confidentiality and to obtain feedback on my research plan and tools.

Six mothers were interested and participated in an Auckland-based pre-fieldwork workshop. None of them was HIV-positive, but all were born and raised in Indonesia, fluent in Bahasa Indonesia, well adapted to Indonesian norms and culture, and had seen or heard about the lives of people living with HIV. Three of them were postgraduate students, two were wives of postgraduate students, and one was the wife of an Indonesian migrant worker in Auckland. They were between 25 and 40 years old. Two FGDs were conducted and they were asked to try their best to position themselves as HIV-positive mothers in Indonesia.

On 23 December 2016, I attempted the first FGD with all six Indonesian mothers, aiming to practise establishing rapport and building partnerships. I began by explaining the aim and the methods of my study. I used terms such as “feminism” and “FPAR”, and introduced my supervisors’ names and their educational backgrounds. I also introduced some visual methods that could be used during the FGD, such as mind-mapping, drawing, and collage. Then, we introduced ourselves to each other and decided to use pseudonyms during the FGD.

Early in the session, I asked them what questions would be good to build rapport with participants. One participant suggested starting the discussion with a story of an HIV-positive woman they know in their community or close network, and the rest of the group agreed. Then, some participants started to share their friends’, neighbours’, and colleagues’ stories related to HIV: a priest who contracted HIV from a blood transfusion, a child with HIV living with her grandmother because her parents had passed away, and a man who sued his girlfriend for transmitting HIV to him. All stories were based on true accounts of PLWHIV in the lives of the participants’ who took part in the mock FGD.

Afterwards, I asked the group to use visual methods to answer the question. “what do you know about PMTCT services?” I divided them into two groups. Both groups chose to apply mind-mapping to express their understandings of PMTCT services, and used sticky paper notes to present their ideas on the map. I began the second FGD by watching them, and then discussing inspiring videos of HIV-positive women in Indonesia raising their children and not disclosing their HIV status to the community. Their activities were followed by creating a problem-tree relating to barriers to accessing PMTCT services among HIV-positive women. The participants then developed strategies to solve the problems making mind-maps and collages. I closed every FGD with icebreaker games to enhance relationships among participants, and group reflections and evaluations of the process, discussing ways to improve my role as a facilitator.

Pre-fieldwork interview practice

To apply FPAR, I practised two approaches of naturalist and constructionist interviews to generate data with the aims of learning how to best understand women's experiences, and build trust and rapport. For the first and second interviews, I positioned myself as an observer; for the third, I role-played as an interviewer and interviewee. I invited the women who joined the previous FGDs to practise naturalist and constructivist interviews, summarising the criteria of naturalist and constructionist interviews and question guidelines. I also had a final practice session separately with my doctoral colleagues and supervisors.

The first practice was between the interviewer, Yeyen, and the interviewee, Ju. Yeyen started the interview with the introduction, purpose of the study, informed consent, and the use of visual methods to facilitate the interview. Yeyen notified the interviewee that she could leave or pause the interview at any time if she felt uncomfortable. The interview started with a question related to self-experience - about how life is after being diagnosed with HIV. Ju was excited to share her story. The interviewer also shared her life experience as a mother, woman, and wife, and described her life with her family. I observed how the interviewer showed her empathy and maintained strong eye contact with the interviewee.

In the second mock interview, the interviewer was Al and the interviewee was Jasmin. Al, who was a Ph.D. student and has experience in qualitative research, acted as the interviewer, asking Jasmin about accessing PMTCT services using the constructivist interview method. She started the interview and listened to Jasmin's responses. Then, Al started to draw a mind map based on Jasmin's ideas and encouraged Jasmin to add some words to the map. I observed how Al tried to offer ideas on how to map their discussion as an initial step to encourage the interviewee to map her ideas.

In the third interview practice, I practised being an interviewee and interviewer. I requested three of my fellow doctoral students (Dina, Al, and San) and my supervisors (Sari and Sharyn) to help me practise my interviewing skills, and to discuss their own fieldwork experiences. I met them individually in their offices, at the university, and in restaurants. From Dina, San, Al, and Sari, I learned about the importance of building rapport, showing empathy, and maintaining good eye contact. They talked at length about probing and active listening to gain an in-depth understanding. They reminded me not to be too rigid with the questions on my interview schedule, but to be open and keep questions relevant to the topic of discussion presented by participants. On 15 March 2017, 12 hours before I left Auckland for my field research, I had lunch with Sharyn, and she emphasised the importance of enjoying my field research as the most exciting part of my doctoral journey. She shared her experience as an anthropologist, about how she preferred not to use recording tools while doing informal interviews and discussions. Rather, after finishing her interviews and discussions, she preferred to write down key information. In the next section I will explain what I learned from the mock FGDs and interviews during my pre-fieldwork.

Lessons to be learned during pre-fieldwork practice

There are lessons from the FGD exercises and interviews that impacted my actual fieldwork with HIV-positive women in Palembang, South Sumatra. I have summarised these into six main important lessons.

First, I learned that the combination of FGD and visual methods was useful to creatively engage participants in sharing collective knowledge, as participants were able to raise individual concerns and have their ideas discussed collectively.

Second, I learned that naturalistic interviewing allowed for in-depth understandings of individual personal experiences and a deep knowledge exchange between the participants and me. Furthermore, it was challenging to be a good empathetic listener. I maintained my position as a naïve inquirer and, as I knew my interview schedule really well, I was able to adjust the questions to be relevant to the topics brought forward by the participants.

Third, I learned to simplify my words. For example, I used simple words (e.g., “women’s perspective”) instead of academic words such as “feminism,” “participation”, “involvement”, and “activities” to represent PAR. For some research activities, I relied on trust and teamwork with my research facilitators who knew the community well to facilitate the FGD, and to observe and take notes of interesting discussions, gestures, and attitudes in the room.

Fourth, I became more aware of the need to organise activities for the participants’ children as highlighted by those involved in the pre-fieldwork, who brought their children to the research 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 Penaggulangan 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, Anggrek, 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 & Ponic, 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	Owning 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 High School /Urban	1st marriage, monogamous; 1st child HIV free; 2nd 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 *warung*)	Senior High School /Urban	Divorced from 1st husband; 2nd husband deceased, was HIV pos.; 2nd marriage, polygamous.
3	Nika	292	2016	Yes	22	Married	Yes	Neg	3	Dependent on husband	Elementary School /Rural	1st marriage, monogamous; 1st and 2nd child were HIV free; 3rd child was taking prophylaxis.
4	Alung	100	2012	No	37	Married	No	Neg	3	Dependent on husband	Elementary School /Urban	2nd marriage as a 2nd wife; One HIV pos. child and one-deceased child.
5	Rini	400	2011	Yes	41	Widow	No	Pos	3	Not work	Senior High School /Urban	Deceased husband was HIV pos.
6	Mawar	300	2011	Yes	41	Married	No	Neg	2	Work at home (have internet café)	Senior High School /Urban	2nd marriage; polygamous; 1st deceased husband was HIV pos.; 2nd husband HIV neg.; Former IDU.
7	Mela	300	2014	No	42	Widow	No	Pos	3	Work outside house (as a house-maid)	Senior High School /Urban	Deceased husband was HIV pos.; Husband was an IDU.
8	Nina	329	2012	Yes	32	Married	No	Neg	3	Dependent on husband	Senior High School /Urban	2nd marriage; monogamous; 1st husband deceased, was HIV pos.; 2nd husband HIV neg., 1st husband was an IDU.
9	Mano	300	2016	Yes	25	Widow	No	Pos	1	Work outside house (barbershop)	Senior High School /Urban	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 High School /Urban	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 High School /Urban	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	2nd marriage, monogamous; 1st husband deceased, was HIV pos.; 2nd husband HIV neg.; 1st child was HIV free; 2nd child was taking prophylaxis. 1st husband was an IDU.
13	Putri	292	2007	No	35	Married	Yes	Pos	2	Work at house (have *warung*)	Senior High School /Urban	1st marriage; monogamous; 1st and 2nd children were HIV free; (2nd 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	1st husband divorced, was HIV neg.; 2nd husband HIV neg.; Former prostitute.
15	Oda	290	2017	Yes	30	Married	No	Neg	3	Work at house (have *online business*)	Senior High School /Rural	1st marriage, monogamous; 1st and 2nd children were HIV free; 3rd child was HIV pos.
16	Xani	300	2007	Yes	35	Married	Yes	Pos	3	Dependent on husband	University /Urban	1st marriage, monogamous. Husband was a former IDU.
17	Bunga	350	2017	Yes	30	Married	Yes	Neg	1	Dependent on husband	Senior High School /Urban	2nd marriage, monogamous; 1st husband deceased, unknown HIV status; 1st child was taking prophylaxis.
18	Mulan	400	2012	Yes	28	Married	Yes	Neg	1	Dependent on husband	Senior High School /Urban	2nd marriage, polygamous; 1st husband deceased, HIV pos.; 1st child died of pneumonia, a sign of HIV; 2nd 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/mm^3): 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/mm^3, 200-350 cells/mm^3 and over 350 cells/mm^3 are estimated to have contracted HIV about eight, four and one year prior, respectively (Lodi et al., 2011)

**PMTCT access relates to comprehensive PMTCT services, including antenatal HIV testing, antiretroviral treatment during pregnancy and after delivery, prophylaxis treatment for babies born to HIV-positive mothers, and formula feeding.

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 4.3: Characteristics of the doctor participants

No.	Pseudonym	Age in years	Length of work experience in years	Participated in HIV programmes	Place of work
1	Yuni ^{F}	32	7	No	Puskesmas
2	Cici ^{F}	37	10	Yes	Private hospital
3	Na ^{F}	27	2	No	Private hospital
4	Ina ^{F}	41	9	Yes	Puskesmas
5	Ra ^{F}	27	2	Yes	Public hospital
6	Anci ^{F}	26	1	No	Private hospital
7	Budi ^{M}	35	8	Yes	Puskesmas
8	Enca ^{F}	33	9	No	Puskesmas
9	Lia ^{F}	38	13	Yes	Puskesmas
10	Rani ^{F}	27	2	No	Public hospital
11	Jo' ^{M}	40	18	Yes	Public hospital

M= male; F=female

Table 4.4: *Characteristics of the NGO worker participants*

No.	Pseudonym	Age in years	Years working in NGOs	Main role	Education level
1	Mon ^{M}	40	15	Outreach worker	Senior high school
2	Pika ^{M}	35	10	Outreach worker	University
3	Wati ^{F}	30	5	Social worker	Senior high school
4	Ira ^{F}	28	5	Social worker	Senior high school
5	Fe ^{F}	30	4	Peer support worker	Senior high school
6	Ni ^{F}	20	1	Peer support worker	Senior high school
7	Toni ^{M}	20	5	Outreach worker	Diploma
8	Adi ^{M}	24	5	Outreach worker	Senior high school
9	Mer ^{F}	30	5	Outreach worker	Senior high school

M=male; F=female

Recruitment of HIV policy makers, and health and women's organisations

A series of individual meetings and group meetings were used to disseminate the aspirations from the group of HIV-positive women, health workers, and NGO workers, to HIV-related stakeholders such as hospitals and *puskesmas*, PHOs, women's organisations, and health organisations (Table 4.5). I met the key informants separately in an FGD or individual meeting.

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 overview of the data generation. For all groups and individuals, I prepared paper and coloured markers and left them on the table for them to see and use as they wished.

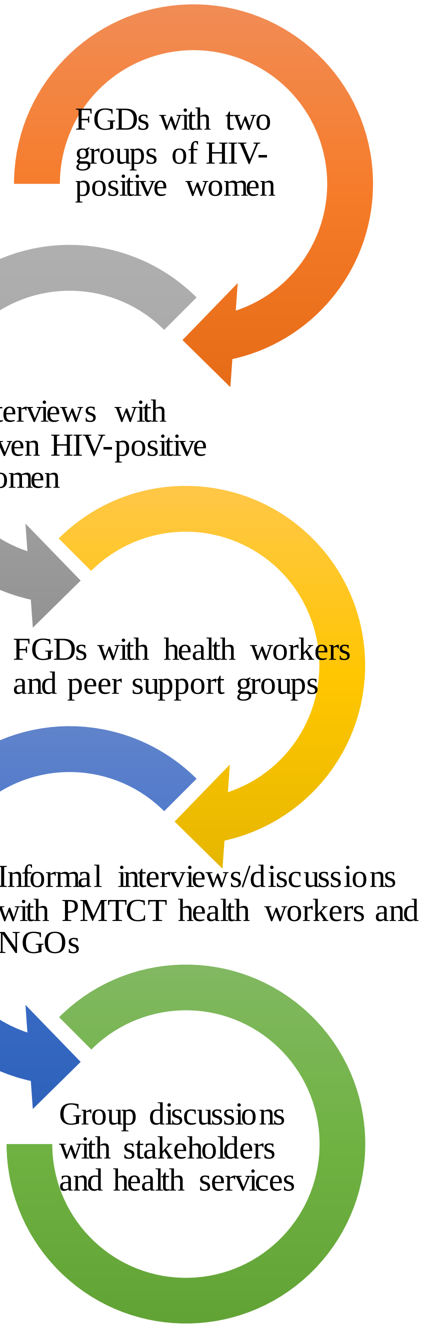


Figure 4.4: Data generation cycle of the field research

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 steps were followed by developing strategies to enable women to access the services, choosing a creative medium to present their message, matching their message with the creative medium platform, practising their performance, having it digitally recorded, and disseminating their performance to their group of choice. The creative outcomes produced by the participants are summarised in Table 4.7 and discussed in-depth in Chapter 7.

Table 4.7: Creative audio-visual outputs produced by 18 HIV-positive mothers

Participants	Output	Title and theme
Group Sehati A	Modified lyrics of "Cuk Ma Ilang" (a traditional song)	Complusory antenatal HIV tests
Group Sehati B	Puppet show for a role play	Comprehensive PMTCT services
Individuals	Poems, drawings and mind-mapping	Being resilient and resourceful HIV-positive women

Figure 4.5: presents the participatory process of collectively creating a creative outcome of modified lyrics. Sehati A decided to modified the original lyrics of a Palembangese folksong, *Cuk Ma Ilang,* in order to deliver their aspiration of better PMTCT services. The lyrics produced, tell a story of women's strength, resilience, courage, and aspirations and needs for compulsory HIV testing for pregnant women. The song's theme was inspired by the experiences of two members of Sehati A whose children were HIV-positive. One of these women had a stillborn baby and believed it was due to her then undiagnosed HIV status. Once the group agreed on using *Cuk Ma Ilang* to capture and impart their message, one group member volunteered to download the original version of *Cuk Ma Ilang* from her mobile phone and share it with the rest of the group members. Together, they brainstormed the key messages to be captured in the song for the right lyrics to match up with the tune of *Cuk Ma Ilang,* which took them about an hour to complete. Then the group practised the song twice and video-recorded it. The practice was done in a soundproof secure room in a public university. I recalled watching the practice and how members were supportive of each other. They reminded each other to be calm and confident. For their final performance, the group then came up with another option, which was to use puppet figures.

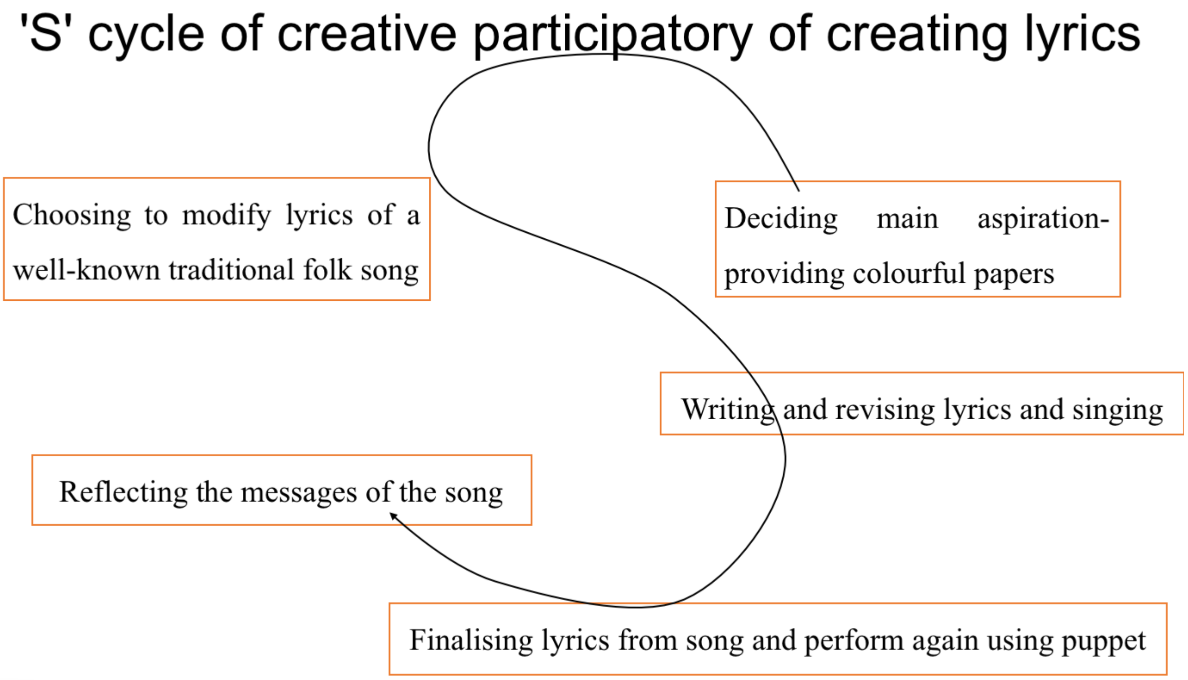
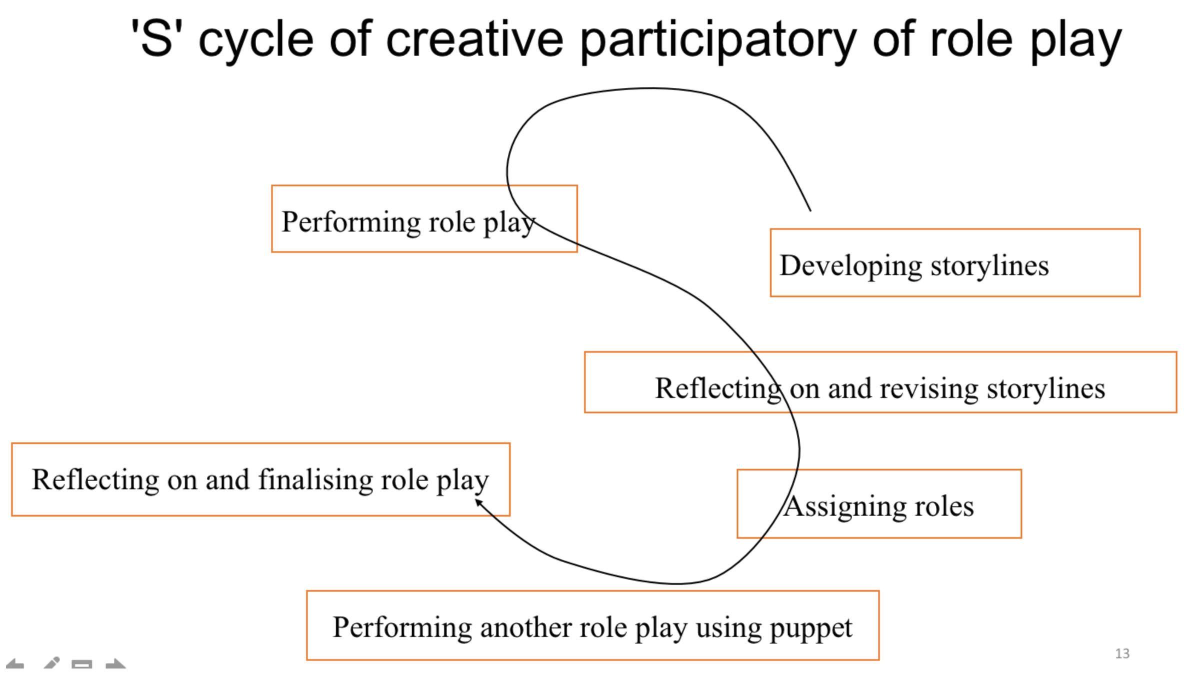


Figure 4.5: Process of creative participatory of creating modified lyrics of *Cuk Ma Ilang*

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

Performing role play

Developing storylines

Reflecting on and revising storylines

Reflecting on and finalising role play

Assigning roles

Performing another role play using puppet

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.

Table 4.8: Creative audio-visual outputs produced by other groups in this study

Participants	Output	Title and theme
Group of Midwives	Modified lyrics of Ya-Saman (a traditional song)	The voice from Palembang midwives' heart
Group of NGO workers	Modified version of Gayung Bersambut (traditional poem) and version of song Dangdut (mix of pop and traditional song)	Communication, Information, and Education I am a HIV-positive pregnant woman
Individuals (An obstetrician)	A video	Embracing people living with HIV, why not?

Finally, this fieldwork included dissemination of the collective knowledge, reflections, and transformations proposed to health stakeholders and organisations, NGOs related to HIV, health workers and community organisations, individually or collectively. The purpose of this was to facilitate greater awareness and advocacy for empowering women's voices to improve the achievement of the four pronged-strategy of PMTCT services. The key informants—midwives, an obstetrician, and NGO workers—were inspired by groups of HIV-positive women and also developed creative visual outcomes to convey their voices to HIV stakeholders, my last group of dissemination (Table 4.8), which is discussed in Chapter 7. In the next two sections, I will outline how data were analysed to generate a richness of aspirations, voices, hope, and the application of research ethics.

5. Data analysis

The FGDs and interviews were transcribed in their original language, the Palembang dialect (local Palembang, which is similar to Indonesian) or Indonesian (*Bahasa Indonesia*). Most field notes and explanations of visual outcomes were written in English. The translation from the original language to English was complex and had the potential to change the meanings of participants' words (Marshall & Rossman, 2016). Therefore, I analysed, coded, and interpreted the data in the source language to avoid misinterpretation (Irvine, Roberts, & Bradbury-Jones, 2008; Temple, 2008). The translation of most quotations and reflections in this research study was conducted with supervisors. The first one was born and raised in Indonesia, and fluent in Bahasa Indonesia and English, and my second supervisor has more than 15 years of work experience in various provinces in Indonesia and is also fluent in Bahasa Indonesia. To ensure accuracy, regular consultations were performed with my bilingual supervisors. In addition, 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 to the theory, concepts, and themes in the study. Saldana emphasised that the data analysis procedures are a means to provide meaningful information to answer research questions, but also, that researchers should use their mind and heart or reflection to generate rich and meaningful evidence.

Additionally, my reflections were noted in field notes to include a description of the research activities, details of participants involved, and overall assessment of the research process and participants' evaluations of activities. I continued to regularly write notes during data analysis and evaluation of my fieldwork and sent my reflection notes to both supervisors for further reflection from their perspectives. Reflection is an important part of data generation and analysis in FPAR (Lykes & HershBerg, 2012: Ponic et al., 2010, Reid & Frisby, 2008). Based on the work of Regmi and Naidoo (2013), reflective analysis started with a descriptive process, followed by assessment and analysis, and evaluation and action. In the first stage, description of interesting outcomes or experiences involved illustration and exploration-related ideas, concerns, and the contexts of reflection notes. Some basic prompts were questions around where I was, why I was there, what I was doing, what other people were doing, what happened, what my part was in this, what parts other people played, and whether the result positive or negative. Assessment and analysis allowed me to think deeper to identify current relevant knowledge to improve issues or conditions related to my study. Some questions at this stage were around what went well, what did not, and how it could be improved. The last stage was evaluation and action, and involved constructing new knowledge from new perspectives. For example, in a similar situation, what I would do differently.

6. Research ethics

Three main issues are discussed in this section. The first involves ethics approval from AUT and in-country research permissions, the second is protection of the participants, and the third explains the ethical challenges during fieldwork.

Obtaining ethics approval and in-country research permission

Ethics approvals were obtained from ethics committees in Auckland and Indonesia. This research was approved by the Auckland University of Technology Ethics Committee (AUTEC) on 7 March 2017 (Reference No. 17/22, Appendix A.a). The in-country approval was obtained from the Research Ethics Committee of the Faculty of Medicine of Sriwijaya University (Reference No. 39/keprsmhfkunsri/2017) on 15 March 2017 (Appendix A.b). The approval 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 comfortable and understood all the information given in this research. Participants had to give written consent and release consent when participating in any FGD or interview. Then, each participant in an FGD or interview was reminded of the importance of confidentiality and to not discuss ‘who said what’ with anyone except the people involved in the group or interview. Finally, the primary researcher was the only one who had access to the participants’ personal details.

Ethical challenges

Ethical issues, including asking for consent to use visual assets from participants, respecting participants’ rights to privacy and confidentiality, and minimising risks for both the participants and the researcher were discussed. A few ethical issues should be noted. Initially, I focused on a group of HIV-positive women and, surprisingly, their husbands then approached me independently to be interviewed after they heard about the study through their wives. It was a challenge to obtain formal consent from their husbands to be involved in the project. I chose to inform the husbands about the project by reading them the information sheet and answering any questions. They then gave their verbal consents to be involved, which were digitally recorded.

The second challenge occurred when the HIV-positive women were willing to role play and perform songs to express their voices and aspirations. Initially, to maintain anonymity or confidentiality, they used masks and veils, changed their clothes, and videos were filmed with their backs to the camera. However, one of the participants was not happy with the recording because she was afraid her children’s friends would recognise her and feel ashamed. For the final visual outcomes, we refilmed their role play and song performance using puppets and different voice tones to ensure confidentiality. The pictures representing community members, women, men, and health workers were downloaded from the internet and the group worked together to make the puppets using glue, wooden sticks, and vinyl (Figure *4.7*). Their performance using puppet shows was recorded in a private family room in a local restaurant or a classroom at the university during semester breaks, to ensure confidentiality. The group understood their copyrights to their production and alongside sharing the video with other groups in this study, chose to upload it to Youtube. During the writing of my finding chapters, I used only the transcripts of their visual outcomes, the reflection messages and screenshots of puppet shows to maintain participant confidentiality.

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.

Epistemology → Theoretical Perspective → Methodology → Methods → Data Collection

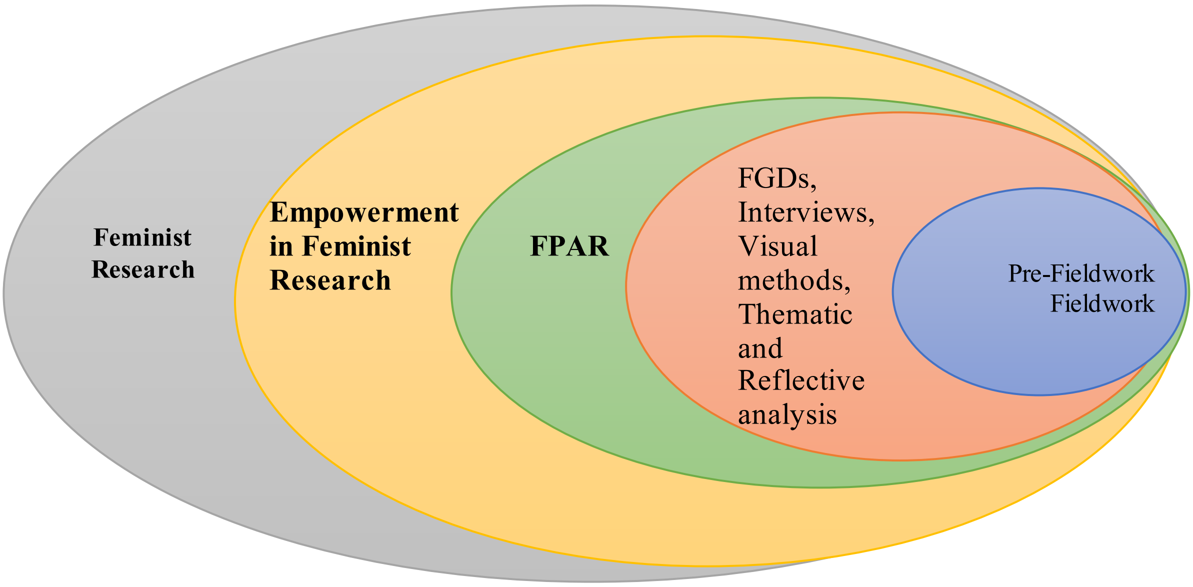


Figure 4.8: Research onion diagram to describe the positioning of the research

(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 women; (2) to create a space for non-discriminatory open dialogue with a critical analysis of gender relations; (3) to centre women within a safe physical environment to communicate with marginalised women; (4) to honour the voices of HIV-positive women through partnership and a variety of creative representation from their expressed aspirations (such as puppet shows, mind-mappings, role play); and (5) to advocate partnership for responsive transformative change. I will critique these principles of FPAR Chapter 8. Next, I explain my primary findings in Chapter 5, 6 and 7.

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 to late detection of HIV for HIV- positive women like Mawar, Oneng and her youngest child, and Mira. The main finding of this chapter is that Indonesian women need to be made aware that every Indonesian woman is at risk of HIV, and there is a need to acknowledge that many factors contribute to the transmission of HIV among women. I start with the story of Mawar.

1. Mawar: Experiences of divorce, substance drugs, and promiscuity

Mawar is of mixed Javanese and Malay (Melayu) ethnicity. She looked young for a 44-year-old woman with her fair complexion and slim body. She wore a Muslim 'Jilbab' (veil), which is not uncommon for Muslim women in Indonesia. She presented herself with good manners and polite demeanour during our discussion. Mawar's story had many complexities and involved her marriage to two men, her experience of being a divorcee, her experimental sexual behaviour, and injecting drug use. The story presented here is drawn from discussions with Mawar through a series of FGDs and informal meetings, followed by online chatting.

Mawar's timeline

Table 5.1: Mawar's timeline

1994	Mawar (aged 20) and Sam (first husband, aged 41) marry.
1995	They have their first child, a boy.
1997	They have their second child, a girl
2009	Mawar (aged 35), divorces Sam.
2009-2011	Following her divorce, Mawar leaves her hometown to move to Jakarta.
2011	Mawar becomes very sick and is diagnosed as HIV positive.
2016	Sam passes away. Mawar (aged 42) marries another man (Udin, aged 37).

Life after divorce

Mawar divorced Sam, her first husband of Chinese Indonesian descent born in Banjarmasin, Borneo, after 15 years of marriage. Following her divorce, Mawar decided to move to Jakarta, and left her two children with her brothers and parents. Mawar recalled that back then, she was young and naïve, and had chosen the wrong friends. At the time, frustrated with her married life, she thought that her future was bleak: "I did not care about my life"; "my friends introduced drugs and discotheque lives, which I enjoyed it very much back then”. She perceived herself as going astray (*tersesat* [58]) for two years.

Mawar decided to return to Medan, North Sumatra, after she became very ill in 2011. Aged 37, she was hospitalised three times, in a prestigious international hospital and diagnosed with chronic gastritis. She was not once recommended to take an HIV test. Mawar sought a second opinion from a small community clinic, where she was diagnosed with HIV. Recalling this experience, Mawar said: “I would have died without knowing my illness”. It was confirmed that her CD4 count[59] was 120 cells/mm^3, which indicated her white blood cells (leukocyte count) were low, and therefore, she was prone to infectious diseases.

At the time of the fieldwork, a few years after being diagnosed with HIV, Mawar was still uncertain how she became infected with HIV. She was not sure whether she was the one who transmitted HIV to Sam or the other way around. Sam, who was much older than Mawar when they got married, was a businessman and had travelled frequently for work. Mawar was almost certain that he had visited sex workers when away on business. Mawar asked her ex-husband Sam to also take an HIV test, and it was confirmed he was positive. Sam took ARV treatment the year after he was diagnosed but unfortunately he was not compliant with the treatment schedule and died in 2016. Mawar recalled:

> As for Sam, his CD4 was over 400 cell/mm$^{3\cdot}$ He was not eligible to take the ARV medicine at that time [to start ARV straight away, the patient needs to have CD4 below 400]. Sam’s lifestyle was a mess, his haemoglobin[60] level always dropped; therefore, he needed a regular blood transfusion. He also did not adhere to the ARV rules, and sometimes forgot to take the medicine (Mawar).

In the year that Sam passed away, Udin, a civil servant or *PNS* and five years younger than Mawar, proposed to Mawar. After being a divorcee for seven years, Mawar decided to marry Udin. When I asked how she fell in love with Udin and whether she had disclosed her HIV

---

[58] “*Tersesat*” is a term used to describe someone, who has broken with religious or social norms, such as having sex outside wedlock, injecting drugs, or drinking alcohol (read Morgan, 1987).

[59] CD4 (cells/mm^3): CD4 cell count, the level of white blood cells (or an indicator of immunity level), is frequently used to measure how long a person has contracted HIV from their seroconversion. People living with HIV who have CD4 less than 200 cell/mm^3, 200-350 cells/mm^3, and over 350 cells/mm^3 are estimated to have contracted HIV about eight, four, and one years prior, respectively (Lodie et al., 2011).

[60] A protein in red blood cells that carries oxygen throughout the body.

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).

Yasmin would never be happy living with Udin because she thought Yasmin was a gold-digger (*cewek matre).*

Mawar admitted that she was struggling to forgive Udin and felt betrayed. Mawar continued to share her story with me, even after I left Indonesia to return to Auckland. At the end of 2017, she told me that Udin promised if he ever had another affair it would be okay for Mawar to divorce him. Mawar wrote to me in a private Facebook message:

> My problem is that I am very stressful ☹ with Udin's previous love affairs. An affair could be nice and beautiful [*selingkuh itu indah*] but impacts on the sufferings of the wife. ☺. I am so stressful, I cannot sleep and I am always on the alert and suspicious of him. He drives me crazy. He nearly got married to that woman (Yasmin) but Allah (God) gave His guidance from my night prayer (*Tahajud*). I was with him every day, but he was able to have a time with her in a hotel during his office hour. How come? I only found out about his affair in April 2017. Now, we both always in fights. If I am depressed, I kick him out of my house, but when I am in a good mood, I let him back in. That is my life now, I feel disturbed (Mawar).

In the narratives, Mawar's journey, as a divorcee in her second marriage, gave an account of the dynamics of women's vulnerability to HIV, and social, cultural, and religious tensions. Next, I discuss the tensions that enhance HIV transmission among women and their partners– lessons from Mawar's story.

Reflecting on Mawar's vulnerability to contract or spread HIV

Mawar's account highlighted how a woman's vulnerability to HIV infection is determined by a complex intersection of gender roles, HIV social stigmatisation, and marital and economic status. Three tensions arose in Mawar's story: 1) negative social judgements of divorcees; 2) deception within marriage; and 3) poor knowledge about HIV.

Tension of being a divorcee

The first tension that I discuss relates to sexual life after divorce. Mawar's and Yasmin's life stories shared several consistencies related to negative perceptions and the stigmatisation of divorcees, such as their presumed involvement with sexual experimentation, drugs, and nightclub parties. After her divorce, Mawar's decision to leave her hometown and try a 'new' life in Jakarta, reflected her agency over choice, as well as the tension over the choice between choosing to fight the stigmatisation, or fleeing from other people's judgement of her divorcee status. Being a young female divorcee can be highly stigmatising in Indonesia, and such women can be seen as a failure in Indonesian society, influenced by the mainstream hegemony of the 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, particulary 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 example, Mawar maintained an ideal marriage based on cultural norms, but suffered from mental health problems, being stressed about her husband's deception within their marriage.

Poor knowledge related to HIV

A third tension of Mawar's story was the poor awareness and knowledge of the danger of HIV transmission. Mawar and Udin had unprotected sex, despite knowing Mawar's HIV status; this was a situation of serious concern as Yasmin may also have been at risk of contracting HIV. Stigma around HIV, combined with inadequate knowledge of HIV transmission, prevention, and treatment, may have resulted in poor (and potentially fatal) health outcomes for Mawar, Udin, Yasmin, and their other sexual partners. Indeed, late diagnosis of HIV for Mawar might have contributed to unexpected transmission to other people around Mawar, such as her sexual partners and IDU peers sharing needles or syringes.

In a health setting, poor knowledge and awareness of HIV risk among health workers may contribute to a lack of awareness of the need to offer HIV assessment or treatment to clients. Silence surrounding STIs, including HIV, may be related to the "narrow sexual morality" of health workers (Bennett, 2015, p. 162). Not once was Mawar offered an HIV test, although she sought medical consultation and treatment from a top private hospital in Medan, North Sumatra (the fifth largest city in Indonesia). Fortunately, she sought a second opinion about her health condition and finally knew of her HIV-positive status.

To summarise, the interplay of elements discussed in the foregoing sections may contribute to the complex story of HIV vulnerability among women and their partners. In Mawar's narratives, it was evident that being a divorcee may trigger unsafe sexual practice and drug use as a reason to flee the social stigma of divorcee status. On the other hand, a divorcee may be pressured to marry again to reinstate acceptable marital social status. However, a lack of awareness about contracting HIV, deception, and silence surrounding HIV in health settings may exacerbate HIV transmission among people in Mawar's life. Oneng told a different story to that of Mawar.

2. Oneng's story: A low-income HIV-positive widow raising an HIV-positive daughter

Oneng (41 years old) was a mother, the breadwinner of the family, and a single mother to her six children. She represented the concept of a traditional Indonesian housewife or *ibu rumah* *tangga*. I met Oneng regularly through a series of FGDs and informal interviews, and visited her house during *Eid* (an Islamic religious holiday). Oneng's story revealed the HIV vulnerability of married women (e.g. housewives) and their children, which cannot be excluded from a woman's subordinate status within marriage. I start Oneng's story with listing her timeline, discovering her HIV status, depicting her married life and its complexity, and reflecting on her vulnerability to HIV.

Oneng's timeline

Table 5.2: Oneng's timeline

1993	Oneng and Suleman marry.
1995-2009	Oneng and Suleman have six children. Suleman does not allow Oneng to take birth control.
2009	Aliya (the sixth child) is delivered naturally and breastfed exclusively for five months before starting with solid food, formula milk as well as breastmilk.
2013-2014	Oneng and Suleman decide to live separately.
2015	Suleman becomes very ill and is diagnosed with tuberculosis.
2016	Oneng and Suleman are reunited and live together again. Suleman is diagnosed with HIV and passes away.
2016-2017	Oneng and Aliya (7-year-old-daughter) are diagnosed with HIV. Oneng and Aliya take ARV therapy.

Finding out about her HIV status

Oneng's story was about her shock after being told by her doctor that her youngest daughter was HIV positive. Oneng discovered her HIV-positive status only after her youngest daughter, Aliya, became seriously ill in 2016. Aliya had a mouth cyst, which was associated with HIV:

> I was very upset and asked for repeated tests. Angrily I asked the doctor, "how come my daughter got this HIV?" The doctor replied *Bu* (Mrs), you should know how HIV was transmitted to your daughter." I asked him "what do you mean?" I was very angry. The doctor told me if I did not trust the test result, I could have another test, but I had to pay for it. (Oneng)

With tears falling on her cheeks, Oneng recalled being referred to a bigger hospital for surgery on Aliya's cyst. Aliya's operation was considered to be a special medical treatment due to her HIV status. Aliya was discharged within a few days after surgery but re-admitted due to slow recovery. Oneng spent the Eid holiday in the hospital, and Aliya was absent from school for two months. After Aliya recovered, Oneng met with a peer support worker when collecting Aliya's ARV medicine in a VCT centre. Oneng was encouraged to undergo an HIV test and the result was positive with a CD4 count of 155 cells/mm^3. Her CD4 level indicated that Oneng 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, was that none of the health workers followed up with Oneng or had her take an HIV test. Unfortunately, at that time, Oneng did not know HIV could be transmitted through sexual intercourse with Suleman, and that HIV could infect her last child, Aliya, either during her pregnancy, delivery, or feeding (Alia has been breastfed initially, then fed with solid food, formula milk as well as breastmilk in her first six months).

Reflecting on Oneng's and her daughter's HIV vulnerability

Oneng's narrative revealed a lack of knowledge and awareness of HIV during her pregnancy, the complexity of her married life, and described a wife who sought treatment for her husband's wellbeing, despite his infidelity. This section explains the HIV vulnerability of Oneng and Aliya. Oneng's life account highlighted how a married woman can contract HIV due to an interplay of subordinate status within marriage, economic dependence, and lack of integrated HIV testing for pregnant women in midwifery and tuberculosis clinics. This section discusses two tensions in Oneng's story: 1) being a dedicated or good wife and mother within societal expectation of an Indonesian woman; and 2) being naïve and powerless.

Being a wife and mother within societal expectation of an Indonesian woman

A first tension is the societal expectations reflected in Oneng's story of her as a wife and good mother. Oneng was a prime example of a good and a caring mother of her six children. She was an obedient wife who would not take any contraception without her husband's approval. Oneng could be seen as an 'ideal' wife under Indonesian marriage law, which states that a wife's duty is to maintain family harmony (GoI, 1974). When Suleman fell sick, he demanded that Oneng look after him, and she complied, consistent with the gendered role of a good wife. After her husband passed away, she maintained her role as a mother and also became the breadwinner for her six children. Oneng, and most Muslim women, are taught that being a mother is a prestigious and high status job in Islam as per the famous hadith: "Paradise lies at the feet of the mother" (Pappano & M. Olwan, 2016, p. 1).

Oneng's understanding of life was also constructed from the social and cultural values of being a dedicated wife and mother. A wife is expected to be pliant, obedient, and subdued towards her husband within the patriarchal values of Indonesian society (see Chapter 2). The Indonesian Marriage law stipulates the male as the leader of his family and the head of a household, while a wife is a household manager (Indonesian's Marriage Law, 1974 Article 31, 34; see Chapter 2). Oneng's account followed the existing hegemony of *Ibuism*, whereby a woman's roles and 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 last child became infected with HIV without undertaking any high-risk behaviours. Only in recent years (since 2013) has the Indonesian MoH promoted antenatal HIV screening for pregnant women in the general population. In 2016, the MoH passed another regulation requiring integration of HIV screening within the Minimum Standard of Health Services in primary health settings such as *puskesmas*. However, the implementation of this programme in Palembang began only in 2017, and in limited numbers of *puskesmas*.

The first two stories, of Mawar and Oneng, depicted an interplay of the different elements of being HIV-positive women within and outside marriage, as well as against the different backgrounds of their differing socio-demographic characteristics. Mawar was more likely to contract HIV after her divorce, while Oneng exposed HIV risk to her last child during pregnancy and after delivery without being aware of her own HIV status. The next story concerns Mira, who was diagnosed with both HIV and syphilis during her second pregnancy.

3. Mira’s story: Seeking PMTCT services with her husband

Born in 1996, Mira presented as a smart, talkative, and confident young woman. She worked at a textile factory in Kerawang, West Java, for a few years after graduating from senior high school in South Sumatra. Later, she returned to Palembang to get married, after Kuyung (21 years old) proposed to her when she was 19. Mira’s story was told to me over six FGDs, which were followed by private online chats. Mira’s lived experience involved her marriage with a MSM, her agency of engaging her husband to undertake HIV testing and preventing HIV from being transmitted to her child, and institutionalised HIV stigmatisation and consequent discrimination in health settings. I start her story from her timeline, followed by Mira’s and Kuyung’s efforts to seek a caesarean delivery for her second child in a public hospital, discriminatory practice during her delivery, how Mira and Kuyung may have contracted HIV and syphilis, and understanding the pressures of marriage with a MSM. This section ends with my reflection of Mira’s lived experience for her right to raise an HIV-free child (Najmah, et al., 2019).

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)

Vulnerability and discriminatory practice

During the recovery process, Mira recalled some incidents when she received blame and discriminatory treatment from the health workers. For example, one of the nurses had said, "you knew that you were HIV-positive, why did you decide to be pregnant and deliver your baby?". Other health workers mocked Mira, by giving signals to their peers to indicate that she was HIV positive, while she was present; one health worker gestured the letters of HIV on her hand to let other health workers know of her HIV status. She was also not comfortable with the body language shown by visiting doctors and medical students, and at the same time, she felt hopeless. She was angry and disappointed with the treatment she received, but there was not much she could do aside from hoping for some empathy from the nurses, midwives, or doctors at the hospital. A few months into her recovery, she asked about family planning and Intra Uterine Devices (IUDs) in the same hospital but was rejected after she disclosed her HIV status. Fortunately, after 18 months of being treated with preventative HIV medication, Toleh, her son, was declared HIV-free. At the end of 2017, Mira posted a Facebook message to her social network praising the miracle that her son was confirmed healthy.

Syphilis and HIV vulnerability

This sub-section explains the HIV vulnerability within Mira and Kuyung's marriage. During her second pregnancy, in 2015, Mira recalled going to the *puskemas* to check her vaginal rashes and itchiness. The test results confirmed she had syphilis and HIV with a CD4 count of 350 cells/mm^3. Feeling shocked, Mira told Kuyung and demanded he take a blood test; Kuyung was diagnosed HIV with a CD4 count of 450 cells/mm^3. Either Mira or Kuyung was probably infected with HIV about four years earlier (Lodi et al., 2011). Both Mira and Kuyung were referred to the VCT clinic for ARV treatment in the tertiary referral hospital in Palembang and accessed PMTCT services to prevent HIV transmission to their child.

Mira was unsure whether it was she or her husband who acquired the HIV or syphilis first: "I did not know who got it first, he [Kuyung] is a man" (Mira). At some point, she was also suspicious that she might have acquired HIV from an unsterile syringe used by one of the staff at a family planning clinic. She also thought it was possible that she got infected by her sister, who was HIV-positive, when she was looking after her. However, the risk of getting HIV from

---

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 married, he may continue his sexual relationships with his male partners and not disclose these to his wife (Najmah, et al., 2019; Stephen, 2015).

Toni was also an MSM and recalled his own experience of having Anto as his male sex partner. Due to pressure from Anto's parents, Anto decided to marry a woman, but still maintain his relationship with Toni. He and Anto's relationship did not last long. Anto warned him not to discuss their relationship, because, as he explained, "you would find my corpse in this house if you disclosed our sexual relationship with my wife" (Toni). He added, "how come we are honest regarding our sexual orientation" to our female partners within heterosexual hegemony. Toni added that being gay is considered sinful and cursed; consequently, an MSM might be afraid to take an HIV test or ARV treatment due to the stigma attached to being both HIV positive and gay. In addition, denial of HIV among MSM is rampant, as some of Toni's peers thought they were still healthy and that it was impossible to contract HIV. Next, I reflect on HIV vulnerability among married women within heteronormative-spaces (for example, within a traditional family context) and challenges for young HIV-positive spouses when trying to access PMTCT services.

Reflecting on Mira's story

In Mira and Kuyung's marriage, there was a complex interplay of deception, stigmatisation around homosexuality, heterosexual morality, and HIV stigmatisation in the health setting. Kuyung might have engaged in homosexual sex prior to his marriage with Mira; however, there was no knowledge about whether Kuyung had continued his sexual practices with men after his marriage to Mira. Kuyung had never disclosed his sexual orientation to Mira, nor sought to do an HIV test, although he was infected with syphilis one year prior to Mira's being infected. Fortunately, after Mira was diagnosed HIV-positive, she was determined that her husband would treat his HIV and syphilis, and both of them made efforts to protect their baby by accessing PMTCT services, including caesarian operation.

This couple was eager to seek a caesarean section and disclose their HIV status; however, they failed to have their rights to the operation granted. The risk of mother-to-child transmission can be reduced to less than two to five percent if women access effective treatment during pregnancy, follow safe labour practice, and formula feed (or breastfeed according to certain rules and medication) (De Cock et al., 2000; MoH, 2013a; Tudor Car et. al., 2011; WHO, 2019b). A caesarean section is seen as the main alternative for safe delivery for pregnant women living with HIV with limited CD4 and viral load test. With her agency, being a young

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*).

This section starts with stories of the HIV transmission of 18 HIV-positive women in this study, “The complexity of HIV transmission: individual experience”. It is followed by a reflection of a visual outcome that was developed by a group of HIV-positive women, “The complexity of HIV transmission: collective knowledge”. The third part is my reflection on the stories of Mawar, Oneng, and Mira. The section concludes with a discussion about the complex intersection of Indonesian women’s vulnerability to HIV, that I refer to as the “spider’s web”[65].

The complexity of HIV transmission: Individual experience

The first part discussed the complexity of HIV transmission based on the individual experiences of participants. The complexity of HIV transmission was depicted in Figure *5.1*. Each of the 18 HIV-positive participants indicated her vulnerability to HIV was because she had been exposed to one or more risk factors. The 12 women in the study group believed they had been infected with HIV from their husbands who were either former IDUs, practising unsafe sex, polygamous, or MSM, as the women said they had never exposed themselves to high-risk behaviours related to HIV. Six of the 18 HIV-positive women believed they had been infected by their husbands, who had practised unsafe sex during their travel to HIV-prevalent areas in Indonesia such as Bali, Medan, Jakarta, and Papua. Three of them also reported that their husbands may have practised polygamous marriage as well as had extramarital sex partners, and may have also accessed female sex workers.

Four women thought that they had been infected with HIV through other means, as their husbands were confirmed as HIV negative. Two women believed they had been infected with HIV due to their own behaviours, such as having unsafe sex or injecting illicit drugs. Two of the 18 HIV-positive women were unsure about how they had contracted HIV. They suggested they may have been infected by unsterile sharp equipment while delivering their children in unsafe rural health settings, or while they were in beauty salons. Later, two of the 18 participants (Niki and Mano), either after their husband’s death or divorce from their husband, decided to become a female sex worker due to financial pressure, even though they had been confirmed as HIV-positive (see Figure *5.2*).

---

[65] The metaphor of a spider’s web, as coined by Holden (2003), was utilised to illustrate how many factors enhanced an individual’s level of vulnerability to contracting HIV. Some elements in the micro and macro levels of women’s lives interplay to result in disparate health outcomes for women, including their contracting and spreading of HIV (Bowleg, 2012; Holden, 2003).

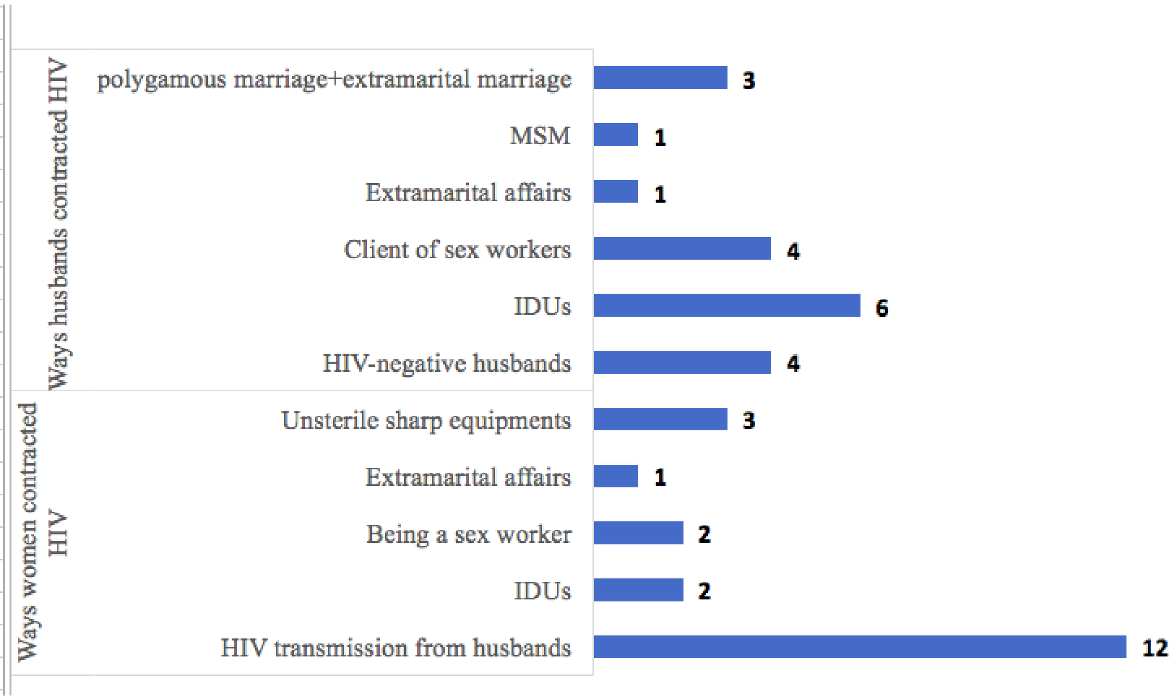


Figure 5.1: How the HIV-positive women in this study believe they contracted HIV (n=18)

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.

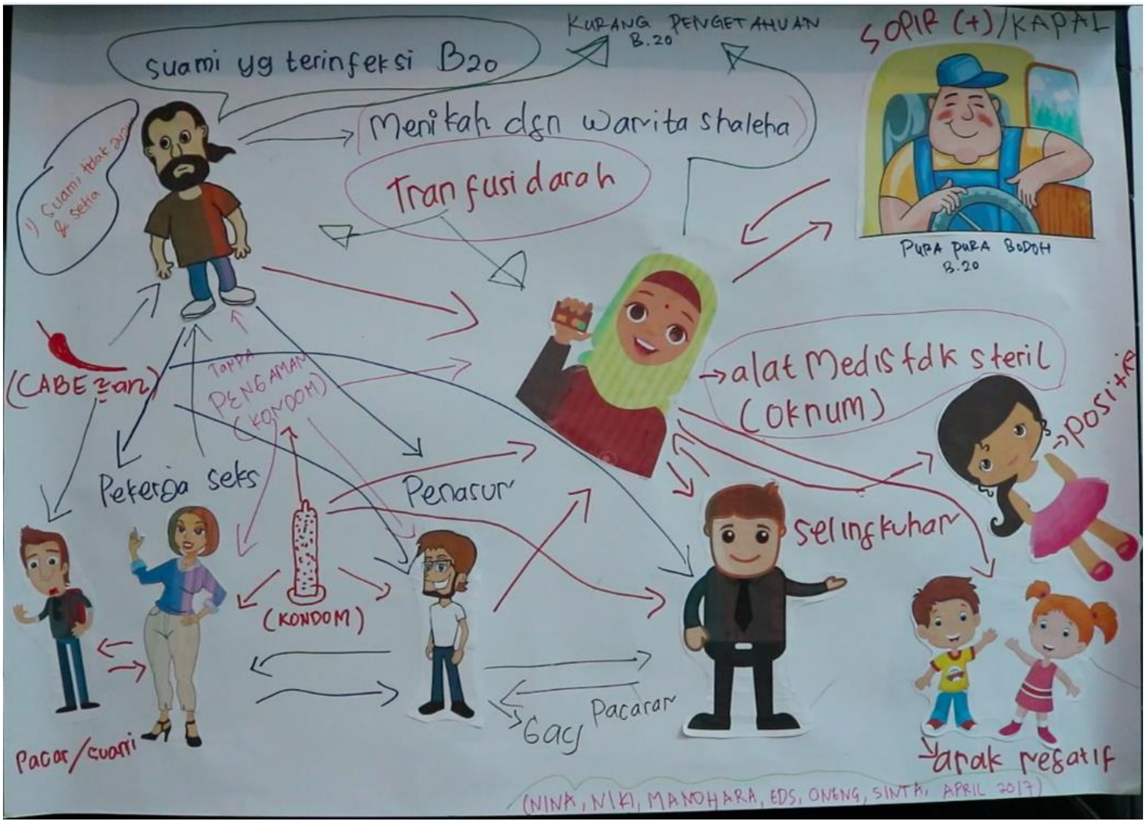


Figure 5.2: Collective knowledge related to the complexity of HIV transmission among women of childbearing age (Created by Sehati A, April 2017)

Note: This collage shows, based on an FGD with six HIV-positive women, there are multiple, possible modes of HIV transmission.

Third, a married woman might have affairs with other men, particularly if her husband is a driver (*sopir*) or shipman (*kapal*) (long-distance relationship). This woman might have an extramarital marriage (*selingkuhan*) with an MSM who might contract HIV from other men (living with HIV). Fourth, *Cabe-cabean*, female teenagers who are students in a school or university and working as sex workers, might transmit HIV to their male partners, either boyfriends or male clients. Fifth, a woman who is a divorcee or widow may have intimate relationships with other men or may choose to be a sex worker to earn enough to feed her family. Sixth, a female sex worker might have a husband or boyfriends. Seventh a man or a woman may get HIV from unsterile medical equipment (*alat medis tidak steril*). Sadly, women infected with HIV might transmit HIV to their children (*anak positif, negatif*) through pregnancy, delivery, or breastfeeding. Taken together, the results in these first and second parts of a complex story of transmission have provided evidence of HIV transmission within or outside marriage among *ibu rumah tangga*. The third part of this complex story of transmission reveals the uniqueness of HIV transmission based on the lived experiences of Mawar, Oneng, and Mira.

The complexity of HIV transmission: The stories of Mawar, Oneng, and Mira

The three lived experiences presented in this chapter are unique. To some extent, there were shared commonalities, although their life circumstances were vastly different. The first consistency was the late diagnosis of HIV after a family member became gravely ill. Mawar and Mira became very ill before going to a clinic and finding out their HIV status, while Oneng only knew of her HIV status after her last child was diagnosed with HIV, one year after her husband's death. Unfortunately, late diagnosis resulted in a missed opportunity of early HIV prevention and detection through a clinic. Oneng transmitted her HIV to her daughter through pregnancy, delivery, or breastfeeding, while Suleman (Oneng's husband) and Mawar were offered HIV testing after repeated hospitalisations. Both Suleman and Mawar passed their HIV infections to their partners. Secondly, the level of deception practised in their marriages was high. A husband may have extramarital sexual relationships with multiple women, or may regularly visit brothels (e.g. Oneng's husband and Mawar's first and second husband), and husband or wife may inject illicit drugs (e.g. Oneng's husband and Mawar) without disclosing this to their spouse or health providers. A husband also may have sex with other men before or during their marriage (e.g. as did Mira's husband).

To some extent, the three stories also differed. First, unlike Oneng, Mira knew of her HIV status during her pregnancy. As a result of Mira's knowledge and attitudes related to her baby's HIV vulnerability, she made an effort to access PMTCT services and reduce the risk of transmitting HIV to Toleh, while Oneng transmitted HIV to Aliya without knowledge of her own or her husband's HIV status. Second, Mira differed from Mawar in that Mawar could not get Udin (her second husband) to find out his HIV status. Mira, with enough knowledge and experience of HIV, was successful in encouraging Kuyung to undertake an HIV and syphilis test. The third difference was that Mawar was financially independent and could have left her husband (Udin) without jeopardising her financial situation, but Oneng maintained her marriage despite family disharmony, and was therefore exposed to the risk of HIV from Suleman.

Indonesian vulnerability to HIV: Complex intersections

This fourth section on the complexity of HIV transmission in Indonesia summarises the first three parts of a complex story of HIV transmission among Indonesian women. HIV vulnerability among Indonesian women is depicted in Figure *5.3*, which illustrates that married men and women have a role in HIV transmission to males and females in the wider population.

Figure 5.4 depicts HIV vulnerability, showing the intersections of individual, intimate, cultural, and social spheres, and heterosexual hegemony in Indonesia. The intersection of each element illustrates how both wives and husbands are contributors to HIV transmission within and outside marriage. Figure *5.3* complement existing frameworks developed by the Indonesian MoH (2012: Figure *1.3* in Chapter 1) and Riono et al. (2004) portraying the dynamics of HIV transmission among married women and children in Indonesia and two Asian studies in Thailand and Vietnam (Figure 2.1 in Chapter 2). Figure 5.4 extends my proposed framework of Indonesian women's vulnerability to HIV based on the literature discussed in Figure *2.2* in Chapter 2.

Every Indonesian woman (including an *ibu rumah tangga)*, therefore, needs to be aware that she is at risk of HIV, even if she does not undertake any high-risk behaviours related to HIV. The metaphor of a spider's web symbolises the finding that knowledge about HIV should be increased to enable mothers to consider various ways to prevent transmission to their children. The metaphor illustrates that men and women may have a role in HIV transmission to both men and women in the general population, and not just the key population. For example, in the present study, Oneng (female, wider population) was infected with HIV from her husband (male, key population); however, without Oneng's awareness of her HIV status, she transmitted HIV to her last child during pregnancy, delivery, or breastfeeding. Oneng's husband Suleman, may have been infected with HIV through his affairs with women (female, key population), or through his IDU peers. Suleman's peers, other IDUs, may have had partners too. Thus, Suleman, within and out of marriage, spread his HIV to his partners, his wife, and his daughter.

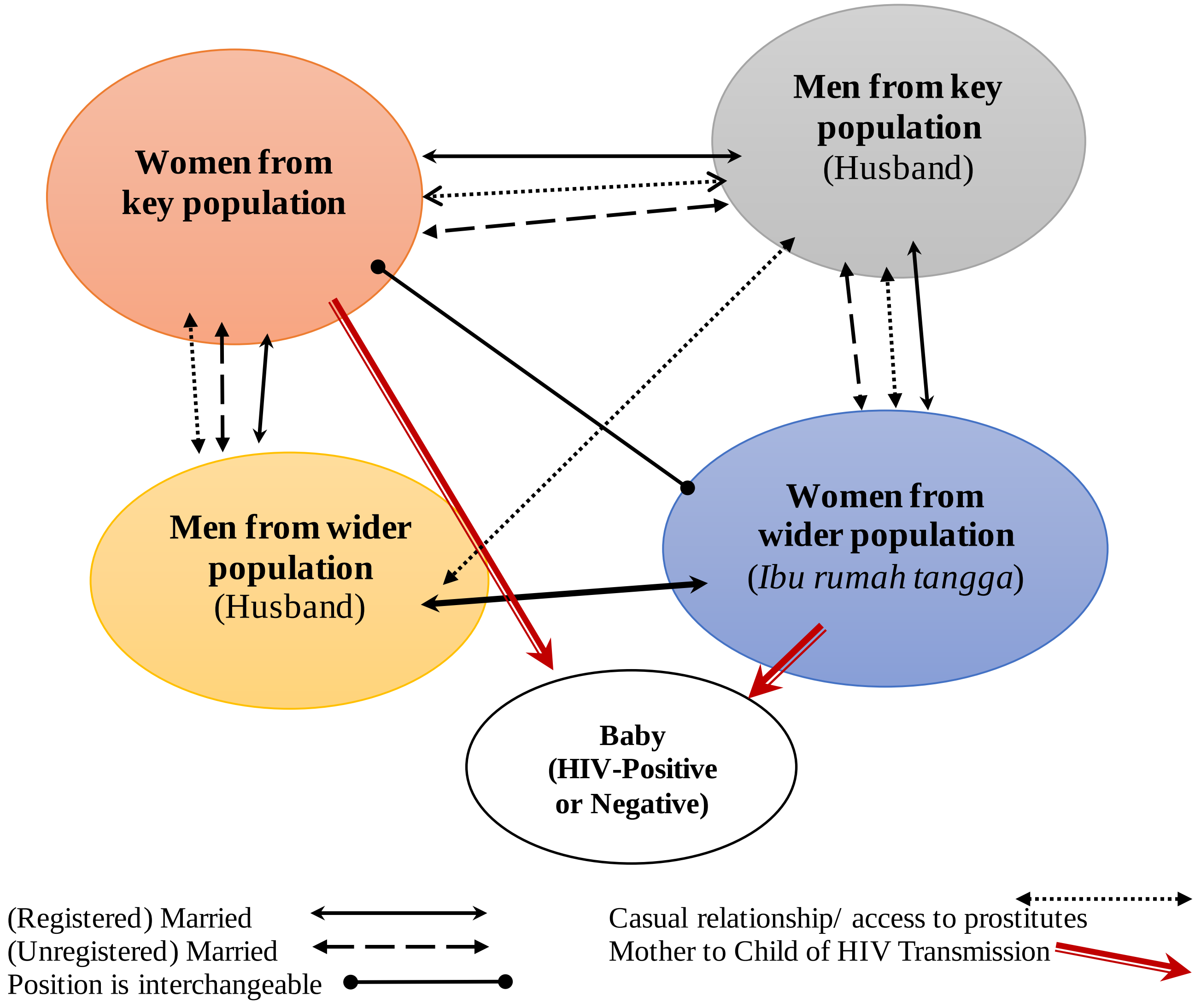


Figure 5.3: The spider's web of HIV transmission among heterosexually married women and men in Indonesia

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

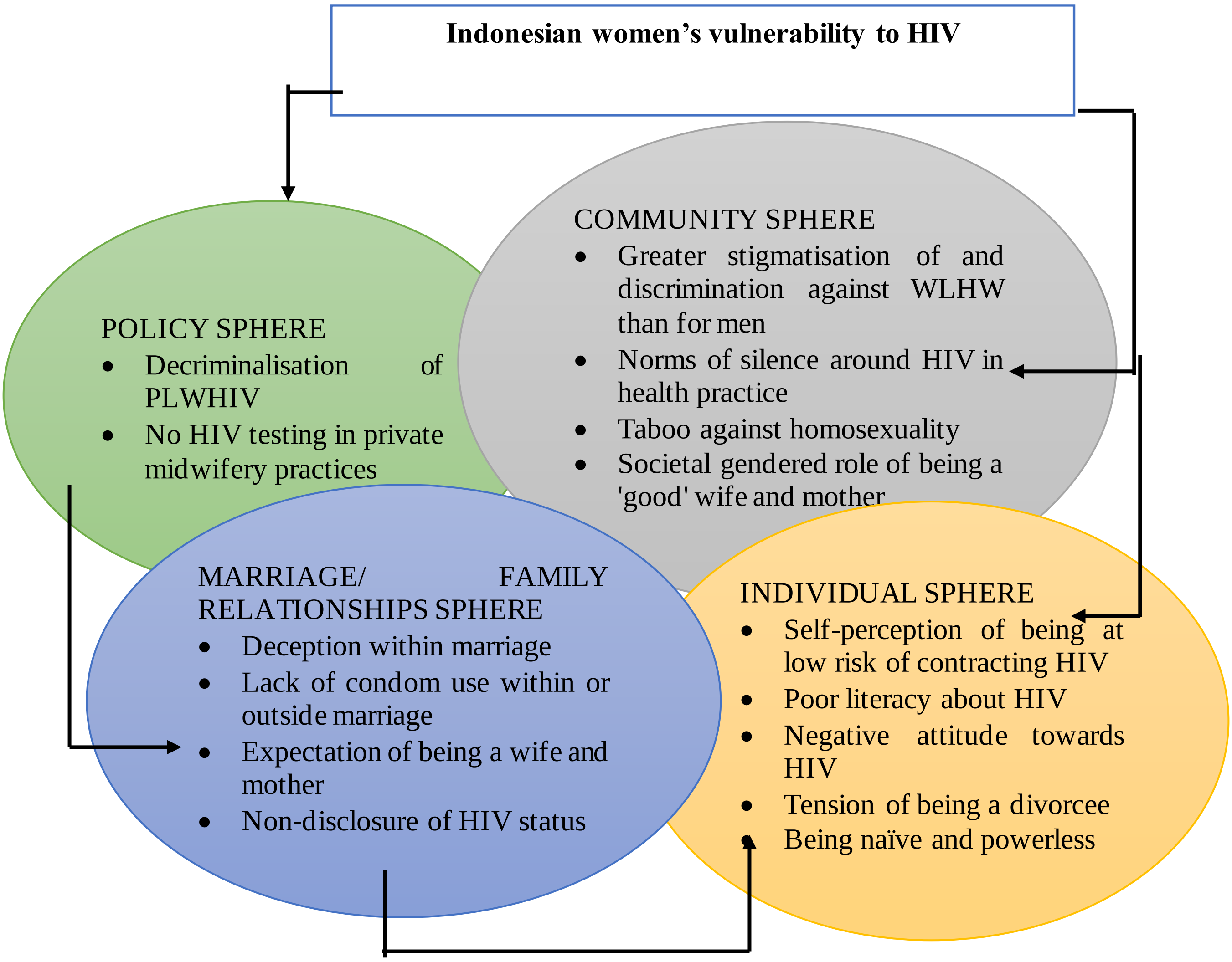


Figure 5.4: Multiple layers of factors influencing Indonesian women's vulnerability to HIV

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 contract HIV through their unsafe homosexual practices (Stephen, 2015). Further, women who experience divorce are considered as failures in their married lives and may punish themselves by having multiple partners or using (and injecting) illicit drugs, and may therefore contract HIV. These women may pass HIV to their partners or husbands after getting married. Unfortunately, condom use is extremely low in Indonesia both among groups with high-risk of exposure to HIV as well as among married people (MoH, 2013e, 2014a; Praptoraharjo et al., 2016b). Condom use is negatively associated with prostitutes and extramarital sex, and this view is reinforced through dominant social, cultural, and religious values and norms (Praptoraharjo et al., 2016b).

5. Summary

HIV amongst women of reproductive age in Indonesia is growing due to a number of factors. However, Indonesian women, particularly wives and mothers (*Ibu rumah tangga*), are considered by the Indonesian government and policy makers to be at low risk of being infected with HIV. First, if women are married there is an assumption that they are safe from contracting HIV. Second, even if a husband knows or suspects he has HIV he may deny it, thus, rendering his wife highly susceptible to contracting HIV. Third, those infected with HIV often fail to disclose their status. Fourth, the shame associated with HIV means that no one talks about HIV openly. Fifth, even when there is acknowledgment of HIV, people have very little knowledge of it. Sixth, there is limited HIV screening of pregnant women, so women unknowingly pass HIV on to their babies, and poorly integrated health services mean there is little support for them. For these reasons, every Indonesian woman is at risk of contracting HIV, and mothers are passing HIV on to their babies. Of course, multifaceted elements in women's lives may contribute to the violation of their rights to access PMTCT services, to enhance their awareness of their HIV risk, access antenatal HIV tests, and prevent HIV transmission to their children. These elements are discussed in Chapter 6.

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 third section provides further understandings of how morality, a patriarchal culture, and being a married woman in Indonesia either discourages or encourages women to access the services. The analysis of gender morality and gender discrimination is based on four women's experiences of accessing PMTCT services. I argue that as long as barriers to accessing PMTCT services continue, women will be unable to prevent the transmission of HIV to their children. Thus, women's rights to protect their children by preventing transmission of HIV to themselves and their babies are being violated.

2. Getting tested or not

HIV testing among pregnant women in the general population has been integrated into antenatal care services in Indonesia since 2013. A number of regulations were passed by the Indonesian MoH between 2013 and 2017 to support the implementation of HIV testing for pregnant women. The regulations provide guide on HIV screening, provider-initiated testing and counselling (PITC), comprehensive PMTCT services, and guidance to navigating the shared financial responsibility and commitment to providing HIV programmes for the early diagnosis of HIV-positive pregnant women. Nevertheless, in reality, there are challenges faced by healthcare providers and healthcare workers in implementing antenatal HIV testing, as seen in Nika's narratives below.

> At first, I thought, I had a normal blood test. After I took the test, a health worker told me: 'please wait outside'. I was waiting for hours until the last patient had gone home. 'What happened to me? I asked myself wearily. I asked another health worker. She said 'No worries, just sit down, and a nurse will come to get you soon.' Finally, a counsellor came and told me that my HIV test was positive. To my shock … and three days later, a midwife, who was my neighbour and work in that *puskesmas*, was gossiping with my neighbours about my HIV status. My family and I were expelled from our village straight away. Social stigma … had cornered me …failed me… punished me …as if I were not a good woman…not a good mother… watch your mouth… those people working in health … get the right education. (Nika, HIV-positive mothers with three kids)

Nika's narrative revealed the story of how she and her family were expelled from their village (*kampung*) after the community found out about her HIV-positive status following her antenatal HIV test in a local *puskesmas*. Nika said that she and her family were victims of social gossiping and social stigma. At the time of this study, Nika actively participated in a few FGDs. Nika was from a low economic status family, had an elementary school education, and was raised by her grandmother in a remote rural area on the outskirts of Palembang City. She 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*, or people being curious about other people’s affairs, was widely practised. In Nika’s story, the midwife, being Nika’s neighbour, behaved unethically. Furthermore, she may even have been trying to discover Nika’s HIV status from her colleague. Other stakeholders, a group of doctors, argued that disclosing Nika’s HIV status was a normal part of the anamnesis procedure. However, most health workers who have had training on HIV topics argued for the protection of patients’ confidentiality and said that health workers should not respond to their peers’ curiosity for the sake of being *kepo*. Every health worker has to respect patients’ rights to privacy and confidentiality.

During my observation, I overheard a health worker (unethically) asking an HIV-infected pregnant woman: “I am sorry, I am really curious. How come you got contracted with HIV?” On another occasion, I happened to hear a group of peer support workers and health workers discussing a patient’s HIV status and her private life. I wondered how future HIV training could emphasise the need for respect and protection of patients’ confidentiality within the existing social norms of *kepo* in Indonesia.

Health workers’ intention to protect their peers

Some of the health professionals in my study also argued that disclosing the HIV status of their patients was to protect other health workers or other patients housed in the same room as the HIV-positive patient. A senior male obstetrician recalled his experience of being told to use the term ‘*insus*’ (an abbreviation of ‘*intensifikasi khusus’* or special intensification or HIV), a code to tell his colleague about an HIV-positive patient. He explained, “…even a cleaning service would easily know the patient’s HIV status” (Didi, July 2017). He assumed that the midwife’s action in regard to Nika was part of an attitude of solidarity amongst the health workers to protect their peers and warn them to take precautions when dealing with HIV-positive patients. I wondered if these health workers understood that their *kepo* attitudes and ‘good’ intentions to save their peers from HIV transmission could result in adverse impacts on their patients’ lives. For example, Nika and her family were expelled from her village for good, leaving her family and friends. After her HIV confidentiality status was breached, gossip about her spread by a health worker in her village.

Lack of professionalism

My participants attributed the breach of patient confidentiality in Nika’s case as a reflection of poor professionalism in antenatal HIV screening programmes in Palembang. Various health 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.

Lack of coordination and distrust between host organisations

At the national level, antenatal HIV screening has been mandated as a part of the Maternal and Child Health (MCH) programme under the section of *Bina Kesehatan Ibu Hamil* (Pregnant Women Health) within the Department of *Bina Gizi and KIA* (Nutrition and Maternal and Child Health). However, at a regional level at the South Sumatra and Palembang PHO, two managers or coordinators (*kepala bidang*) of the HIV programme and MCH programme were responsible for the HIV screening programme, along with HIV managers in both provincial and district PHOs affiliated with and overshadowed by this programme compared to the roles of MCH managers.

> Antenatal HIV screening has not been implemented optimally. At the national level, managers of HIV programme and MCH programme have worked together. There is also hope that programme managers at regional level, South Sumatra and Palembang provincial PHO, will work well together. Our provincial health programme has also been directed by the Indonesian MoH to make HIV test as a mandatory and a part of routine blood testing for all pregnant women. (Nana, Global Fund Manager, a female doctor with Public Health expertise, FGD HIV stakeholders)

In practice, both HIV and MCH programmes are often disconnected. For example, during a FGD, a coordinator of MCH in Palembang PHO appeared to have less knowledge about antenatal HIV screening than the HIV Palembang PHO's coordinator. Unfortunately, regional challenges on the decentralisation of the HIV programme in Indonesia highlight a discrepancy in top-down coordination from national to regional and local grass root levels (*puskesmas*). Such a discrepancy is not specific to Palembang but also exists in other regions, such as Jakarta, the capital city where the Indonesian MoH is located (Badriah et al., 2018; IPPI, 2017), and Lampung and Surabaya (IPPI, 2017).

A lack of coordination between the HIV and MCH programmes at the regional level may contribute to some distrust between these two parent organisations. The following conversation between two provincial health officers from South Sumatera reflected the distrust and misunderstanding of the *puskesmas'* capabilities to perform rapid HIV testing for pregnant women. Officer 1 was employed as an HIV programme manager (a male nurse) in Palembang PHO, and Officer 2 was a female doctor trained in HIV work, with more than 13 years' experience working in *puskesmas.*

> 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 private hospitals and private maternity clinics, or a narrow perspective on morality issues surrounding HIV (see the fourth section of this chapter).

MoH regulations have been passed to support healthcare workers to exercise their rights to perform an HIV test for their patients. Between 2013 and 2015, it was mandated that HIV testing for all pregnant women in the general population of Indonesia change from compulsory to be offered (*wajib ditawarkan*) (MoH, 2013, pp. 9-10) to compulsory to be tested (*wajib dites*) (MOH, 2015, p. 8). These regulations were specifically for any provinces with generalised epidemic (for example, Papua) and concentrated epidemic (such as, Palembang, study setting, see Chapter 2). The health workers participating in this study knew about this regulation, but were hesitant to pressure pregnant women to take an HIV test. All of the discussants were very clear that none of them could force a pregnant woman to do an HIV test and they had to respect the rights of the patient to make a decision. Ideally, any pregnant woman who rejects HIV testing should be referred to a *puskesmas* or hospital with a VCT centre, to receive HIV counselling. Unfortunately, the inadequate quality of HIV training amongst midwives hinders understanding of the importance of HIV testing and therefore, efforts for referral.

In summary, this first section has discussed the challenges women face in getting tested for HIV. HIV testings are the first step to accessing early treatment with ARV therapy from PMTCT services, for those who need it. Appropriate and relevant patient counselling and the readiness of health workers to offer antenatal HIV testing are key to successful antenatal HIV testing of women in the general population. However, inadequate readiness of health workers and healthcare providers, as well as the normalisation of confidentiality breaches, may reduce women's motivation to get tested for early detection of HIV and stop HIV-positive women accessing further comprehensive PMTCT services for preventing perinatal risk.

3. HIV positive: Experiences after the diagnosis

This third section examines the experiences of a pregnant woman after her HIV diagnosis and her challenges delivering HIV-free babies The following story illustrates the challenges Ani faced in her efforts to prevent HIV transmission to her baby. Ani's experience can be categorised as an example of the failure to use the opportunity, or missing the opportunity, for early ARV therapy during pregnancy to prevent perinatal HIV transmission, and then for treatment for her infant after delivery. Dr Lia, who is a 38-year-old doctor with 13 years' experience treating HIV pregnant women, retold Ani's story. The story reveals the complexity of accessing ARV treatment for both Ani and her infant (Text-box 6.1).

The first part reflects the perception of Doctor Lia who treated Ani. Dr Lia argued that Ani's failure to access comprehensive PMTCT services was because of Ani's self-stigmatisation, the lack of HIV testing for children aged under 18 months, and the lack of capability of general practitioners to diagnose HIV-positive children. The second part highlights the normalisation of fears among health workers when dealing with HIV-positive patients, which leads to the provision of poor services. The third part reflects health workers' and peer support workers' perspectives of the complex and confusing referral system faced by women attempting to access comprehensive PMTCT services. This section highlights that cultural attitudes to HIV, including normalisation of fears of HIV-positive patients, may lead to mistrust between patients and their health providers; therefore, violation of the rights of an HIV-pregnant woman to fair and confidential treatment may be a significant barrier to preventing perinatal HIV transmission.

Ani first visited Dr Lia's *puskesmas* in 2016. She came in looking very pale and frail. She was asked to take blood tests, including an HIV test; the result of which was positive. Following this shocking result, Ani stopped coming to the *puskesmas*. One year later, Ani came back looking much worse; by this time, she was presenting with late-stage HIV. She came to Dr Lia wanting to have her baby checked for HIV, but unfortunately, although the baby was confirmed as having symptomatic conditions, not once was an HIV test offered. When asked why there were no follow- ups with Ani or her baby, Dr Lia explained that HIV tests for infants only started in 2017 in Palembang, a year after Ani came back with her baby for testing. Ani was gravely worried that her child might be positive and needing treatment but Dr Lia explained that at that time, there were no HIV treatments for infants, and HIV treatments for adults differ to those for infants.

Text-box 6.1 Ani's story: Difficult access to ARV treatment

In this section, my analysis draws upon the detailed case study of a woman with HIV. Ani, a patient of Dr Lia, whose experience highlights the challenges faced after her patient, was confirmed as HIV positive during her pregnancy and then sought an HIV test and treatment for her baby. The section is divided into three parts: 1) how the health system failed Ani, a pregnant woman living with HIV, when she tried to access comprehensive PMTCT services; 2) the fears around dealing with HIV-positive patients; and 3) how the complex and confusing referral system became a significant barrier to preventing mother-to-child transmission of HIV.

How the health system failed Ani

After hearing Dr Lia's story about Ani, I heard Dr Lia and nine other doctors in a group discussion reflect on challenges faced by pregnant HIV positive women attempting to access early care and HIV tests for mother and baby. From Dr Lia's story, it was not clear what caused Ani to stop coming to the *puskesmas*. Dr Lia and the other doctors offered the term *self-stigma*, referring to the negative feelings that people living with AIDS (PLWAids) have, such as feeling unfair, disgusted and dirty. For example, a HIV-positive woman may think that healthcare workers may be disgusted when treating them and therefore, that she might be discriminated in a health setting. Consequently, a HIV-positive woman thinking this way might hide and stop coming to health services.

> PLWHIV may suffer from self-stigmaisation. They may assume that there is bias or unfair treatment of PLWHIV (*diperlakukan tidak adil*), and that health workers feel disgusted (*jijik*) when dealing with them. In reality, we, health workers, treat the HIV-positive patients as other patients (*padahal pelayan kesehatan biasa saja*). (Dr Lia, a female medical doctor, HIV specialist, FGD)

This assumptions of the healthcare workers about self-stigmatisation however, might not be true. After all, Ani did revisit the *puskesmas* for further consultation. When Ani came back to visit the *puskesmas,* it was over a year since her first visit, and she was gravely ill. She looked thin and frail and was diagnosed with tuberculosis (a common infection in the late stage of HIV). One possible reason for Ani's returning to the *puskesmas* might relate to her awareness of the severity of her HIV, and that she wanted to make sure her baby was getting the right treatment as early as possible. Ani had to travel back and forth a few times to the *puskesmas* to access a HIV test and treatment for her child. Unfortunately, HIV testing for babies under 18 months old was not available in Palembang. Dr Lia acknowledged that a general practitioner had less capability of diagnosing the HIV status of a baby than a specialist, and the baby should therefore be referred to a paediatrician. I believe that it was essential for Ani to be given the right information and offered HIV treatment for herself and her baby. Had Ani been referred to see a paediatrician in the PMTCT clinic, her infant would have been offered appropriate treatment.

I argue that the lack of follow-up by patients was largely caused by the bad rapport between healthcare providers, breakdowns in communication, lack of transportation to go to PMTCT services in tertiary hospital, and poor coordination between healthcare providers, clinic management, and peer support groups (i.e., NGOs). Key to early detection of HIV and compliance with ARV treatment are appropriate and timely counselling, support by a trained and experienced counsellor, and effective communication and coordination between health services related to HIV programmes (MoH & UGM, 2015). Unfortunately, not all healthcare providers have the relevant training, skills, and experience, or the time and energy to listen to their patients, and refer patients to counsellors in *puskesmas* or hospitals with VCT centres or peer support groups (i.e., NGO workers). For example, among the four general practitioner doctors with an HIV speciality that I met, only one was happy to give his telephone number to patients for further consultation after they went home. Yet, Ani may depend on her husband's income and may be fear to disclose her HIV status to her husband. Sadly, Ani's case involved a *puskesmas* that had VCT service facilities and was assumed to have well-trained healthcare workers on HIV prevention and treatment (such as a referral system and PMTCT services).

In this section, it has been explained that after being confirmed as HIV positive, not all HIV-positive pregnant women will decide to access comprehensive PMTCT services. Unlike Nika, adhered to therapy to prevent HIV transmitting to her baby with her husband's support, Ani's experience may represent many losses of follow-up cases and missed opportunities to reduce perinatal risk. Barriers from Ani's narratives were her self-stigmatisation, inadequate information about her disease and HIV risk for her baby, and the lack coordination among healthcare providers. There was little information about Ani's husband in this narrative, so I presented other stories (Anti and Lela's, and Adel's stories) in the third theme on gender morality of this chapter (see p. 177), in which husband's decisions about their wife's health needs may have violated the women's rights to access PMTCT services.

Health workers' fears of working with HIV positive women

One possible factor that limit women from accessing PMTCT services is the health workers' fears of dealing with HIV-positive women. Comprehensive HIV knowledge among healthcare workers is low in Indonesia, and may exacerbate fears and anxieties for healthcare workers treating HIV-positive women. Previous studies in Jakarta and Aceh found high levels of stigmatisation and discriminatory attitudes towards PLWHIV (Harapan et al., 2013; Waluyo et al., 2015). Unfortunately, studies also suggest that improving HIV knowledge does not correlate with a reduction in discriminatory attitudes toward patients (Liem & Adiyanti, 2013; Waluyo et al., 2015). In this study, participants gave reasons for their fears of working with HIV-positive women. First, they believed that fear of HIV was natural, and second, their avoidance of treating HIV-positive pregnant women was believed by them to be a reasonable 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.

Avoidance along a continuum

Working in a hospital with good universal precautions, however, did not guarantee confidence among specialists treating HIV-positive patients. Zizi, who is a senior obstetrician, often received referrals for HIV-positive pregnant women from his peers. He added that there were only two obstetricians who were comfortable and happy to help HIV-positive pregnant women in Palembang. He acknowledged, “sometimes, my peers do not want to take the risks”. Zizi emphasised that all hospitals have a universal safety precaution standard to meet. He was adamant that, if all healthcare workers diligently followed the universal precautions, using goggles, a mask, blunt needles, and gloves, they would be safe. He demonstrated using a blunt-tipped needle as one of the standard operational procedures in caesarean sections for HIV-positive pregnant women to reduce risk of skin-piercing accidents among healthcare workers. In the case of occupational accidents, reflecting on his own experience, Dr Zizi explained that health workers needed to take prophylaxis medicines to eliminate HIV transmission for themselves. However, not all healthcare settings provide these preventive medicines as a part of universal precautions; hence, avoidance to treat patients with HIV may be a means for some health workers to prevent HIV transmission to themselves.

The insiders explained the discrepancies in practice between the application of correct professional codes of ethics and giving in to personal fears, beliefs, and attitudes toward HIV-positive patients in healthcare settings. Fear and distrust of safety practices and measures enforced in hospitals contributed to avoidance of treating patients living with HIV, the denial of HIV patients’ rights to healthcare and non-discriminatory treatment, and patients’ rights to confidentiality. A lack of correct application of universal safety precautions and non-existent regulations in hospital settings made both health practitioners and patients vulnerable. The example of only two obstetricians in Palembang being willing to help HIV-positive pregnant women reflects the generalised fears among many health professionals in treating HIV patients.

The referral system: Endless red tape

Women had such difficult experiences during the testing phase, as discussed, that they were often too frightened to engage with the bureaucracy of the referral systems. In 2018, there were over 25 VCT centres in Palembang providing HIV testing and counselling, and most hospitals in Palembang provided HIV tests as a part of PITC. However, only two hospitals in Palembang were complying with the third and fourth-pronged strategies of PMTCT services, such as providing caesarean sections for HIV-positive women, and prophylaxis treatment for their babies. One was a public hospital that was both a teaching hospital and the main referral hospital for all hospitals in South Sumatra. There is no doubt that this hospital was overcrowded with limited patient beds. An insider within PMTCT services discussed his concern about the contribution of bureaucratic process to increased risk of HIV transmission to children:

> If the aim of the referral system is to reduce discrimination, we need unique strategies and innovation with the referral systems as we still find HIV-positive children in this hospital. Hence, our focus should be how to undertake early detection of HIV and early treatment to reduce HIV perinatal transmission HIV. This referral system has to be shortened because the earlier ARV therapy for an HIV-positive pregnant woman, the less virus will be transmitted to their children. In the overseas literature, a mother with undetectable viral load can deliver their babies naturally. Here (in Palembang), we have limited CD4 test and viral load test, therefore caesarean operation is still main alternatives for safe-labour practice. (Jo, HIV specialist, a male medical doctor with 12 years of experience treating HIV-positive patient, informal interview)

Additionally, one peer support worker during an FGD asked how a comprehensive PMTCT programme could be implemented properly "if one pregnant patient with HIV should be referred [till] four times with different healthcare providers?" Peer support groups for HIV-positive women expressed the frustration of dealing with endless and complicated referral systems in Palembang. They also encountered the discriminatory practices and denial of services for HIV-positive mothers. Therefore, peer support groups needed to learn to how to navigate the system to obtain referral letters for their patients to receive free antenatal check-ups and caesarean operations.

After arriving at this public hospital, a pregnant woman with HIV faces extensive red-tape to gain access to the services she needs. One of the chiefs of the medical service in the hospital acknowledged that all patients, including those with HIV, "have to be prepared mentally when they come to this hospital, to deal with a long queue before they can be seen" (FGD HIV stakeholders, June 2017). I reflected on my experience of accompanying one of my participants (Mona) for three days of administrative procedures before her caesarean surgery. On the third day, Mona's husband came along as well, and became angry with staff in the hospital after four hours waiting for Mona's in-patient room to be available.

I argue that the bureaucracy surrounding the referral system may have contributed to the low number of pregnant WLWH accessing comprehensive PMTCT services. A HIV-positive woman needs to provide additional transportation cost, as the hospital is usually located in urban areas. In addition, these hospitals' roles were passive as healthcare providers—only waiting for pregnant WLWH to visit their facilities. Based on the reports of one insider in this hospital, in the last decade, this public hospital has treated a relatively small number of HIV-positive pregnant women (approximately 50) who accessed comprehensive PMTCT services, while the implementation of PMTCT services in another private hospital, was considered slow (see Chapter 1). So far, this hospital has treated only four pregnant HIV-positive women from 2012 to 2017. Rumours are rife that this hospital often referred their HIV-positive patients to the public hospital. Three insiders at the private hospital declined the rumour; nevertheless, another insider told me about the slow response of this private hospital in providing PMTCT services:

> After knowing that the pregnant woman who was also HIV positive, the anaesthetist did not want to get involved in the caesarean operation team. He said the hospital did not have any reliable personal protection equipment. But I told him that we had to help this patient, then he asked for the SOP (standard operating procedure) [for HIV patients]). Since then, we have regulated a clear SOP. Nevertheless, that anaesthetist chose to resign from this hospital (rather than to (be) involve in a caesarean team for HIV-positive women). (Dr Didi, a male obstetrician with five years of experience working in a hospital in Papua, Informal Interview)

This second section identified multifaceted barriers to accessing PMTCT services after a pregnant woman has been confirmed as HIV positive. It suggests that there is an interplay of inadequate communication and coordination between relevant services, endless red-tape and avoidance of treating HIV-positive women by healthcare providers, and a lack of standard operating procedures for HIV patients. The dynamics of these multiple factors may have contributed to multiple missed opportunities to prevent HIV transmission from mothers to their children.

4. Gendered morality: Discrimination and women's access to PMTCT services

The third section depicts how dynamics of culture, gendered morality, and gender relations may contribute to additional barriers for women accessing comprehensive PMTCT services. Dominant interpretations of Islam and government policy in Indonesia frame women as being primary carers and upholding the virtue of morality in their relationships and in society. Morality has been defined as "right and wrong or good and bad" (Killen & Smetana, 2013, p. 4) within social relationships based on rules, norms, and local authority. Within a Muslim community, women are "instrumental to men's ethical activities since they view women themselves as lacking full rationality and limited by their biological functions" (Ayubi, 2015,

p. iii). Thus, gendered morality creates unfairness for women within a dominant patriarchial 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'.

This section exemplifies how a double standard on gender role and gendered morality may discourage or encourage women to access PMTCT services. The first part of this section reflects an obstetrician's experience of treating his female patients, Anti and Lela, both diagnosed with STIs, and seeking their husbands' permission to undergo HIV tests. The narratives illustrate how women's rights and their ability to make independent decisions can be impeded by the dominant gender ideology and relationships within marriage and patriarchal systems in healthcare services. The second part reveals how a husband of a WLWH, Tono, did not believe his wife's HIV diagnosis after her delivery. Tono rejected undergoing HIV testing for himself and their baby in the same hospital. His wife (Adel) was silenced, a passive recipient of service, and judged negatively for being *budak kos* (living in a boarding house away from her parents) before her marriage. The third part addresses the professionalism of a midwife and HIV specialist in diagnosing her pregnant patient (Lili) with anal itchiness by asking about a taboo topic related to anal sexual practice within wedlock. Visiting *puskesmas* alone (without her husband's attendance), the woman accessed proper treatment to prevent HIV during her pregnancy.

Stories of Anti and Lela: Needing a husband permission to HIV testing

Anti and Lela's narratives (Text-box 6.2) illustrate the undertaking of HIV testing for married women diagnosed with STIs. Their story was retold by an obstetrician, Dr Didi, in a private hospital in Palembang. The analysis of the story highlights three main concerns: 1) HIV testing and the difficulty of its implementation; 2) unequal rights over women's decisions for their own reproductive and sexual health; and 3) the silenced voices of health professionals.

HIV testing and the difficulty of implementation

In Anti and Lela's cases (Text-box 6.2), Dr Didi followed the procedure of PITC for diagnosing HIV infections of patients with STIs. A healthcare worker with appropriate HIV training, such as Dr Didi, is aware that that low use of condoms and a high number of STIs is "a recipe for HIV surely" (Pisani, 2010, p. 44); hence, he offered an HIV test to the women. The Indonesian MoH Regulation No. 74 (2014d), states that HIV tests and counselling should consider the principles of providing informed consent, maintaining confidentiality, offering counselling and HIV testing, and providing HIV treatment and prevention services.

Nevertheless, in this regulation, there is no requirement for a healthcare worker to ask a patient's partner's permission for them to undergo HIV testing. These narratives from Dr Didi 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 between a wife and her husband, whereby the husband is given the power to determine the sexual health and well-being of his wife.

Within a heterosexual marriage, women's subordination interplays with social hierarchies and can be a significant barrier to HIV testing and early prevention of repeated STI among married women (Bennett, 2015; Meyer, 2002; Risal & Gunawan, 2018; White & Anshor, 2008). The doctor in these cases, a male obstetrician, did not offer HIV and STI tests to the husbands, which indicated these married women were responsible for spreading their STIs to their husbands. The possibility of STI transmission from their husbands was not considered as a possibility.

In this narrative, I argue that Anti and Lela's efforts in seeking treatment for their STIs cannot be separated from the gender norms of Indonesian women within traditional, cultural, and religious norms. However, their subordinate status was felt through the attitudes of workers such as Dr Didi, and within the health institutions generally, despite the increasing education levels of both male and female to overcome gender inequality in Indonesia. Finally, the notion of a man as a virtuous morality guide for his wife extended into the health setting with men; Lela's and Anti's husbands were seen as virtuous users in the health setting. Hence, there exists another difficulty, that of offering HIV testing for husbands.

Silenced voices of health professionals powerless to exercise their professional role

At the end of the interview, Dr Didi asked me to turn off the recording and apologised, asking me not to record our discussions to protect his reputation, but he allowed me to take a note. He revealed a silenced voice with a lack of openness, fear of disputes, and feelings of powerless among healthcare professionals, policy makers, and their patients, that created difficulty for open dialogue between married female patients and health workers. Dr Didi explained his dilemma by telling me that one of the directors of a private hospital once received threats from a patient's family after performing an HIV test without the permission of the patient's husband. Hence, policymakers of the hospital left it for general practitioners and specialists such as Dr Didi, to decide whether or not to undertake an HIV test for their patients.

An Indonesian proverb illustrates the essence of Dr Didi's lived experience with Anti and Lela and their husbands: there is a lemur in the middle of a fight between two elephants, and the lemur is squeezed to death (*dua gajah bertarung, pelanduk mati ditengah*). The lemur is the wife, and the two elephants are the husband and a healthcare provider or a healthcare 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 & Shaluhiyah, 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 returned to the hospital to reconfirm his wife's HIV status and to show his worry of the risk of HIV transmission to their baby.

Adel delivered her baby naturally in early 2017 and afterwards was given an HIV test as recommended by the obstetrician. The result was positive and Adel's husband, Tono, was given the result directly, without the approval of Adel. Tono denied the result and did not want to undertake an HIV test for himself or his baby. He was adamant that both he and his baby were HIV negative without any proof of laboratory tests. Adel also rejected undergoing the test a second time to reconfirm her HIV status.

The midwife, Oci, said that other health workers inquired about Adel's past life from Adel and Tono's family. Adel experienced *budak ko*s (liveing in a boarding house) before her marriage. Oci and her peers assumed that Adel may have had multiple sexual partners before her marriage with Tono. Three days after Adel and her baby were discharged from the hospital, Tono came to the hospital by himself. He wanted to finally determine his wife's HIV status as false positive or not (*istrinyo positif atau idak*) and he was worried "whether did his baby get infected HIV or not through the delivery?" When I inquired further, unfortunately, no additional information was given to either Adel or Tono with regard to HIV prevention for the infant, or ARV therapy for Adel.

Text-box 6.3: Adel's story: HIV diagnosis after the delivery

I am well aware of the strong stigma surrounding HIV in healthcare settings. Healthcare workers and policy makers who are not HIV specialists are both the actors and reinforcers, and a strong element of the discriminatory health system against women living with HIV such as Adel. Tono was able to reject HIV testing for himself, while Adel was tested without her approval or counselling for this procedure. Additionally, after being shocked upon knowing her HIV status, she was humiliated by the negative prejudice surrounding her experience as *budak kos*. Midwife Oci pointed to other midwives within an FGD, saying "we know what is life of *budak kos* nowadays". Midwife Oci and her peers assumed Adel may have contracted HIV because of Adel's sexual life and mobility before marriage. There is a common assumption in Indonesia that if a young single woman is not under her parents' or relatives' surveillance, she may have practised unsafe sexual intercourse (Bennett, 2005; Davies, 2015; Lindquist, 2004).

Reflecting on Adel's story, her independent decision-making might have been compromised by her status, privacy, values within the marriage, patriarchal culture, and religion. I wondered that if Adel had been given proper counselling and a private space to understand her HIV status in a non-discriminatory environment, there would have been the possibility of persuading her to take another HIV test, of engaging Tono to undertake an HIV test, and the opportunity to access ARV therapy for Adel and early propylaxis 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

Lili's story was retold by Dr Ina, a 41-year-old doctor and HIV specialist, with nine years of experience working at a local *puskesmas*. She shared a midwife's experience in dealing with a pregnant woman with anal itchiness.

Asking about a patient's sexual life or practices, even within a marriage, is considered taboo in a healthcare setting in Indonesia. A good Muslim Indonesian woman is raised not to discuss her private life with anyone, including details of her sexual activity with her husband (Mulia, 2009; Nurmila, 2009). Fortunately, the midwife, who was also a counsellor for the HIV programme, was able to make the right diagnosis for Lili. Dr Ina was very clear that it was difficult for any healthcare professional to ask questions about anal sex. Lili was fortunate to come to a healthcare centre where she was treated professionally, without prejudice, and promptly referred to a specialist. Coming alone without her husband, Lili was able to openly discuss the taboo topic related to her reproductive health. In this case, the benefit of HIV training among healthcare workers for providing effective health services and support for patients with STIs and HIV is evident. Lili's story is a good reflection on the importance of having a private space for women to make decisions about their health. I wonder whether the women in this chapter, Ani, Anti and Lela, and Adel, may have had better treatment and prevention of HIV if they had had a private, confidential session with a well-trained health worker within non-discriminatory PMTCT services.

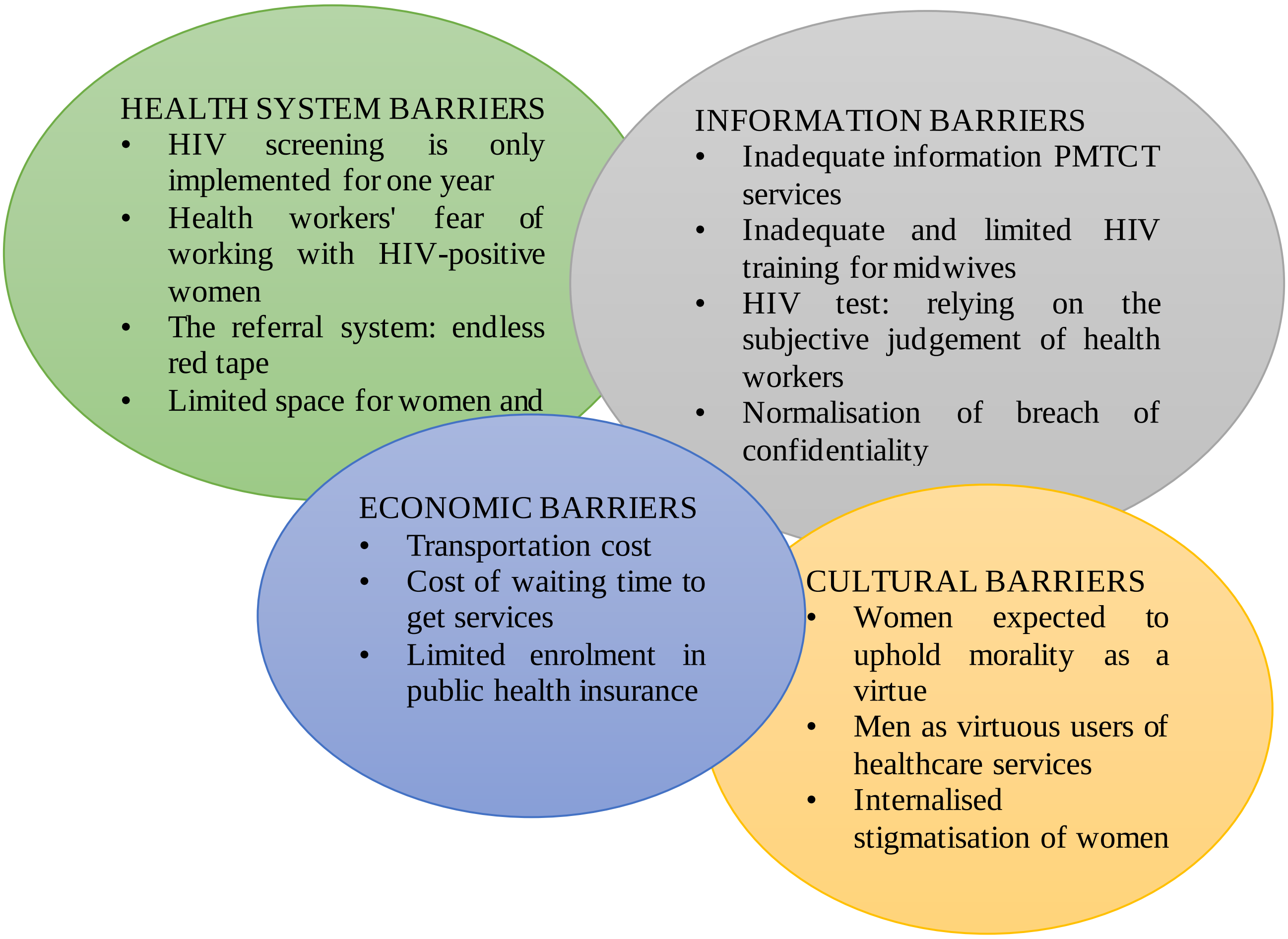
5. Summary

Accessing comprehensive PMTCT services such as antenatal HIV testing and follow-ups for newly diagnosed HIV-positive women, is still challenging considering the constraints of social, cultural, and political norms in Indonesia. The interplay of multifaceted elements in a women's life, and the nature of power within marriage and health settings may contribute to the violation of women's rights to obtain comprehensive PMTCT information and services. Thus, while barriers to accessing PMTCT services continue, women cannot prevent transmission of HIV to themselves and their children.

The first section illustrated challenges in HIV testing implementation among pregnant women in the general population. HIV testing has been regulated as an initial step for the diagnosis of HIV among women of reproductive age, including pregnant women. However, the success of HIV testing may be limited by poor quality counselling, breaches of confidentiality, and a lack of professionalism among health workers. After a diagnosis as HIV positive, there are 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.



HEALTH SYSTEM BARRIERS

- HIV screening is only implemented for one year
- Health workers' fear of working with HIV-positive women
- The referral system: endless red tape
- Limited space for women and

INFORMATION BARRIERS

- Inadequate information PMTCT services
- Inadequate and limited HIV training for midwives
- HIV test: relying on the subjective judgement of health workers
- Normalisation of breach of confidentiality

ECONOMIC BARRIERS

- Transportation cost
- Cost of waiting time to get services
- Limited enrolment in public health insurance

CULTURAL BARRIERS

- Women expected to uphold morality as a virtue
- Men as virtuous users of healthcare services
- Internalised stigmatisation of women

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.

Cuk Ma Ilang Song with lyrics modified by five HIV-positive women in this study

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 my partner [permission] is not as easy as you said.

Verse 2
Hi mothers, don't be ignorant
Today's men may do mischievous deeds
How do we we know they do mischievous deeds
If both partners do not do a 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

(Indonesian version in Appendix D.a.1)

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.

Of the strategies outlined by my participants, two particularly stood out: 1) the ability to be resourceful; and 2) the capacity to attain knowledge. The maps and drawing in this section were selected to illustrate participants' lived experiences of trying to access PMTCT services. Mona and Putri, who were infected with HIV from their husbands, shared their resilience in seeking PMTCT services to realise their dreams of having HIV-free children.

Being resourceful

To Zee, my dearest little angel
By Mona

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

(Indonesian version in Appendix D.a.2)

An HIV-positive woman needs to deal with challenges as a result of her HIV status. Being resourceful means "able to deal well with new or difficult situations and to find solutions to problems" (Merriam-Webster, 2019, para 2). In this study, eleven of the 18 HIV-positive women only knew about their HIV status following their husband's sickness. Seven of these women then dealt with their husband's death and surviving for their children. I share Mona's ability to deal with her situation.

I interviewed Mona during the last trimester of her pregnancy during my research, and had the chance to accompany her to access PMTCT before and after her delivery. At some point during my visit to her office, Mona (30 years old) shared with me her poem and a drawing made by

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.

Being knowledgeable

HIV-positive women need to be well-informed and knowledgeable about their HIV status to eliminate the needed to be *betino harus pinter* (smart) to be able to access relevant and up-to-date information on HIV through online platforms or follow instructions from health workers. The capacity for knowledge includes HIV-positive women having the right information on HIV transmission and PMTCT of HIV, thereby boosting their confidence in having a child free from HIV. In this study, seven women who knew their HIV status during their pregnancy, or planned their pregnancy after being diagnosed with HIV, accessed comprehensive PMTCT services. Putri's story best represents the needs of HIV-positive women for HIV health education and literacy. I met Putri and her husband three times in her small *warung* (stall) in a rented house in the centre of Palembang. Putri and her husband, Joko, had both been HIV-positive since 2007 (Appendix D.c.1).

In 2010, Putri wanted to have another child, but Joko was hesitant, saying "Putri, I had infected you, I do not want to infect our child". Putri, however, was confident that she had all the right information to enable them to have an HIV-free child. In Putri's mind-map (Figure *7.2*), the top line included "having a strong faith" (*keyakinan kuat*), and "having a strong spiritual life" (*shalat, doa, spiritual*). Other key messages were "looking after physical and mental health" (*jaga kesehatan, siap mental*)," searching for relevant information on the internet" (*cari informasi di internet* on PMTCT), and "asking the husband to see a specialist and have some savings" (*ngajak suami ke dokter CST and siap uang*). Putri emphasised the importance of listening to a doctor's advice. From Putri's narratives, it was evident she was well-informed about PMTCT and succeeded in engaging her husband to be well-informed about their rights to have an HIV-free child.

My reflection on Putri's lived story, and five other HIV-positive women who accessed PMTCT services during their pregnancy, is that there are three key elements related to being knowledgeable that enable women to access PMTCT services:

- being optimistic through strengthening spirituality and searching information independently; involving a spouse/partner;
- having on-going communication with healthcare workers related to PMTCT services; and
- having money to access the services, particularly for indirect costs (example: transportation, loss of earnings due to waiting times).

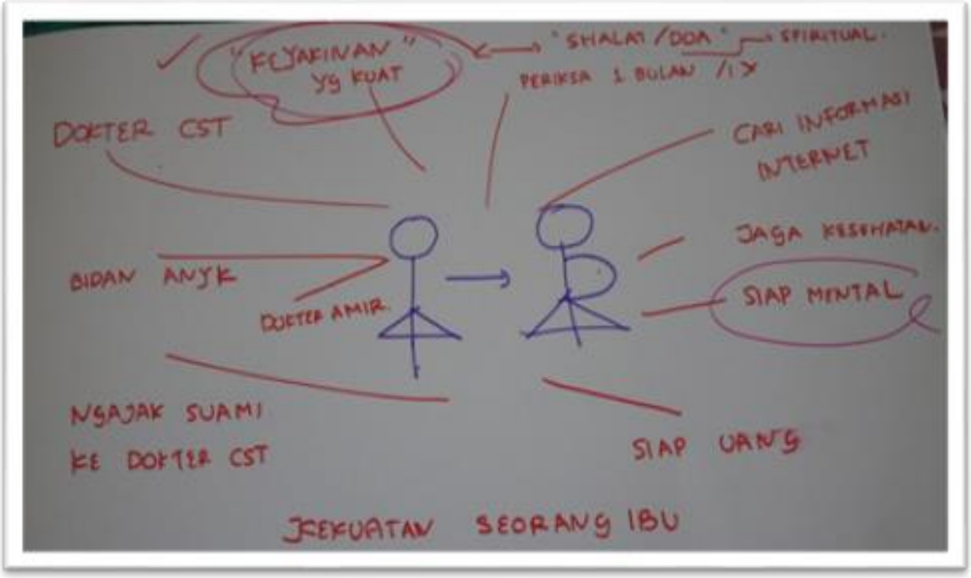


Figure 7.2: Putri's mindmap entitled *Kekuatan seorang ibu* (The power of a mother)

By obtaining the right information, the women became confident that it was possible to have HIV-free children. With the right information, the women were made aware of the importance of maintaining their physical, mental, and spiritual well-being, keeping up-to-date with PMTCT services available, involving their husband in all decision-making, working closely with health providers, adhering to treatment programmes, and putting a financial plan in place for consultation with private health providers and meeting indirect costs for accessing PMTCT services (which were located only in the capital city of South Sumatra).

In the individual sphere, women need to be resourceful and well-informed about their rights to have HIV-free children. The concommitant nature of these strategies, being resourceful, as well as being knowledgeable, equate to a form of resilience, that is, the ability of HIV-positive women to adapt after traumatic experiences such as discovering a husband or child's HIV status and their own HIV status. Women who are empowered to actively and independently seek information about HIV and PMTCT services are more likely to be resilient and enable themselves to access PMTCT services. Arguably, the interplay of these key elements may contribute to enhancing physical and mental health for HIV-positive pregnant women so they can access PMTCT services.

3. Family sphere: What husbands should do to enable women to access PMTCT services

Most women in this study believed that honesty and family support were key to their family fight against HIV. The family sphere includes women's husbands and closest family members such as parents and siblings. The women believed that disclosing their HIV status, as well as acceptance of their HIV status by family members, would contribute to psychosocial support that would help them access HIV care. This topic can best be discussed under two themes: 1) disclosing the HIV status; and 2) acceptance of the HIV status by a women's family.

Disclosing HIV status

Fear of disclosure prevented women from seeking help. In the present study, participant health workers said that most wives would accept their husband's HIV status; however, not all husbands would be as accepting if their wives were diagnosed with HIV. Thus, HIV-positive women need to be honest with their partners regarding their HIV status in order to gain support for accessing HIV care. In this section, I continue with Mona's story.

Mona believed it was very important for her to disclose her HIV status to Adi. She expressed her feelings in poster form with the words "I am HIV positive" (Figure *7.3*). According to Mona, Adi was at first very uneasy after hearing Mona's HIV status. However, Adi was willing to go with Mona to seek the right health treatment, initially for Mona, and later for Adi, himself, as part of his decision to marry Mona. Both visited the VCT centre for consultations with specialists. Adi's decision to marry Mona was not taken lightly. Only after obtaining enough knowledge related to HIV, was he able to accept Mona's HIV status and marry her. Mona did not want to pass HIV on to Adi and her children. Hence, they both worked closely with a specialist for Mona's planned pregnancy and subsequent contraceptive choice.

Later, Adi voluntarily asked me if he could participate in the study, and produced a drawing (Figure *7.4*) depicting a man sitting at a dining table enjoying his coffee and checking his mobile phone. He also drew some pills, referring to the ARV medicine next to his cup of coffee. A shadow behind the man is the ghost of death borrowed from the well-known Naruto Ninja animation. Adi believed that "…everyone will one day leave this world (will die)… but we don't know when and how…." For Adi and Mona, it was important to listen to the doctor's instruction to take the ARV therapy, and also, to enjoy life the best they could … "although the threat of death is just nearby you" (Adi). Adi's drawing exemplified a husband's support 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, Adi's response spreads the message that disclosure, as well as acceptance, is pivotal in supporting HIV-positive pregnant women to access PMTCT services. In addition to husbands, a supportive environment also consists of other family members.

Supportive marriage environment: Acceptance of HIV status

My participants were aware of the strong social stigma and negative views surrounding HIV. For example, they generally associated HIV with sex workers or those engaging in extramarital sex. Nevertheless, the majority of the participants in this study were infected with HIV without undertaking any high-risk behaviours related to HIV. For example, as noted in Figure *5.1* (Chapter 5), 12 of the 18 HIV-positive women perceived that they were infected by their husbands, yet only three participants engaged in high-risk behaviours, such as being IDUs, or sex workers, or having unprotected sex with many partners. However, HIV-infected mothers were still blamed for their HIV and had to deal with negative moral judgements in health settings. Therefore, acceptance of a woman's HIV status, by her husband and close family, is important to enable women to access PMTCT services. I elaborate on this theme by sharing Oda's lived experience with her HIV-positive child (Malin) (Figure *7.5*)(Appendix D.c.2).

Figure 7.5: Oda's mapping entitled *Ibu Oda Kuat* (I am Oda, a strong mother)

I met Oda, her son Malin, and her husband Hasan, several times in hospital during Malin's treatment. Oda only just knew of her HIV status after her malnourished son, who suffered from multiple diseases for a year, was diagnosed with HIV at the age of 18 months. Oda demonstrated that adequate support from Hasan (*dukungan suami*) and her mother-in-law enabled both of them to access ARV therapy. Oda described Hasan as a husband with an angel's soul (*suami berhati malaikat*). Oda also released her worry after her mother-in-law (*ibu mertua*) accepted her and did not blame Oda, despite her husband's HIV-negative status. Hasan and his mother kept reminding Oda and Malin to take their ARV medicine, and regularly accompanied them to visit a hospital, staying focussed on Hasan and Malin's health (*pikirkan anak dan suami*). The notion of being infected with HIV as a trial from God (*cobaan dari Allah untuk jadi lebih baik*) become a motivation for Oda and her husband. Kind-hearted support from close family and a lack of moral judgement strengthened Oda (*Ibu Oda Kuat*) to access HIV care for herself and her infected child.

Family is a central source of strength for women with HIV that can enable them to access PMTCT services. Positive psychosocial factors from family provide emotional and spiritual support for women with HIV, as well as economic support for accessing PMTCT services. Mona and Oda's lived stories revealed how husbands and family members were part of their bravery in disclosing their HIV status. Disclosure needs to be followed by a husband's acceptance that dissolves any internalised stigma for HIV-positive women. Given the gender inequality in Indonesia, where a wife is considered subordinate to her husband, having her husband's support enhances a woman's positivity and optimism to enable her to access the best care for keeping her family healthy. One year after my fieldwork, Mona sent a picture of her second child (Zee's brother, 12 months) who was growing healthy and still taking prophylaxis treatment to reduce the HIV risk for a baby born to an HIV-positive mother (In 2018, Zee's brother was confirmed HIV negative). On another occasion, I met Oda in a hospital and saw Malin recovering from his malnourished condition, gaining weight and learning to walk at the age of three years.

In the following two spheres, community/social and public policy and gender norms, I discuss associated strategies for providing a supportive environment that extends to health care workers enabling women to access PMTCT services. A supportive environment is associated with a social, cultural, or infrastructural environment, where a woman and her family lives, that facilitates protection from factors that could threaten their health (Department of Health and Human Services, 2019; WHO, 1986, 1998). In particular, women in this study were mostly interested in supportive environments within the health services, such as clinics, *puskesmas,* private midwife practices, and hospitals (i.e., VCT clinics). Women of childbearing age need 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.

Figure *7.6* was developed by Oda and her husband, whom I met during Malin's treatment, and includes key messages for doctors (and other health professionals) on the importance of supporting women with the right information (*informasi bagus*), non-discriminatory practice (*tidak stigma*), and using the right language or medical terms when explaining illness (*menggunakan istilah medis*). According to Oda, it was important that the right information relating to HIV transmission be made available in all clinics, including the myths and misconceptions about HIV transmission. On the bottom right of her mind-map, Oda wrote that health workers should know that HIV cannot be transmitted through human sweat, hugging or kissing, sharing food, or drinking (*menular melalui keringat; tidak boleh mencium memeluk; alat makan atau minum bersama*).

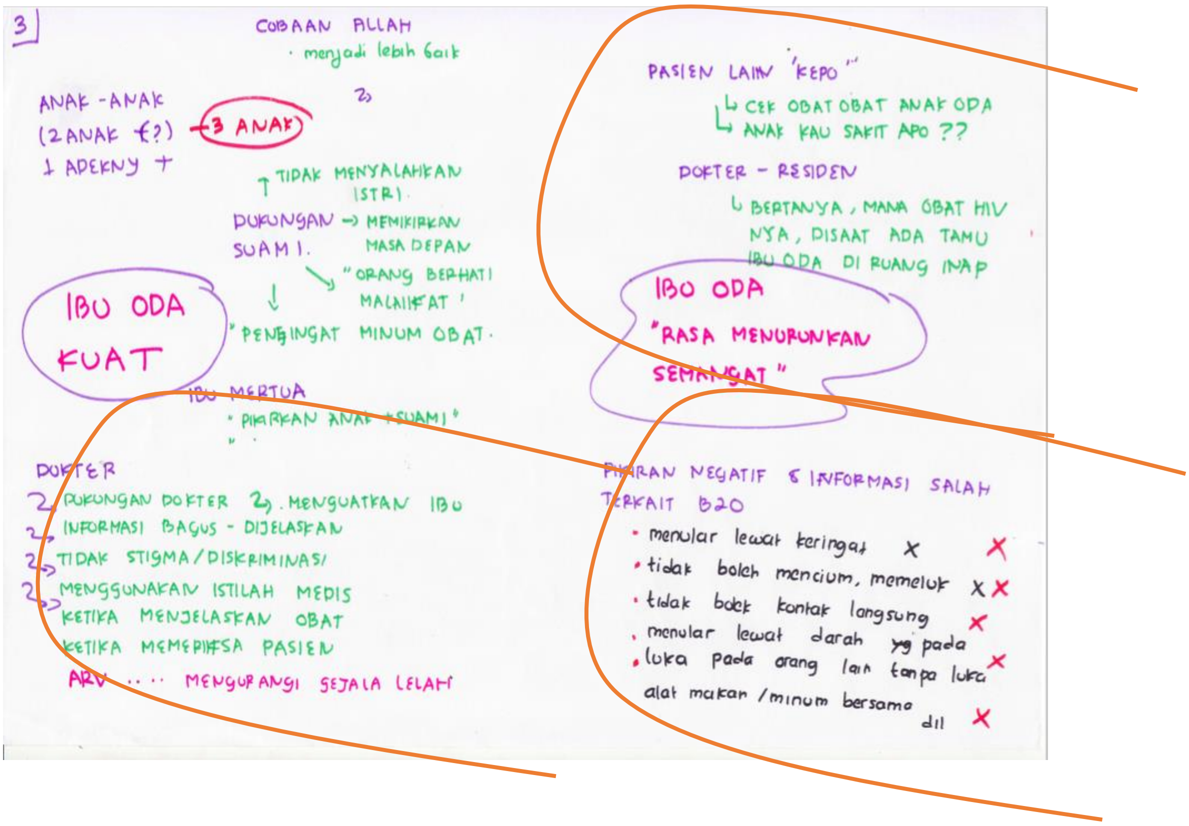


Figure 7.6: Oda's mindmap of patients' needs of supportive health clinic environments

Strategies to solve institutionalised discrimination in health settings

Reflecting on Oda's lived experience and suggestions, further strategies were garnered from the users and healthcare providers in the study, regarding building human resource capacity in PMTCT services to overcome institutionalised discrimination among health workers. In practice, comprehensive HIV training sessions were limited to some health workers who worked in HIV related services, such as in VCT clinics and PMTCT teams in health settings 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, suggested a further mechanism to support peer education, by creating a video that could be spread on social media. He enacted his idea by asking me to record his messages to increase awareness for health workers to embrace patients living with HIV. Zizi was willing to share his professional understandings of dealing with pregnant HIV-positive patients with other health workers. He shared his main message on the principle of a shared responsibility to enhance the care by health workers treating HIV-positive patients. He used a metaphor to explain healthcare professionals' fears of treating HIV patients, saying it was "like fighting in a boxing tournament". He also said that it is better to embrace HIV-positive clients and make them comfortable in health settings than be afraid of them, while also ensuring health workers are aware and protected from HIV. He was adamant that the video needed to go viral through social media such as Facebook, with the title *Merangkul ODHA, ngapo* idak! (Embracing people living with HIV - why not?)(Text-box *7.2*)

> For health workers, HIV is a very scary disease but, in reality, we should not be afraid of our HIV-positive clients. Like fighting in a boxing tournament, it would be great if we fight face-to-face rather than being punched from the back.
>
> Similarly, if HIV clients do not disclose their HIV, it is like someone throws punches to our back. In contrast, if our patients disclose their HIV status, we can apply all precautions to work with them. So we shall embrace them, and make them feel comfortable to come forward, therefore, health workers are well protected.
>
> Well-followed standard operation procedures for HIV prevention and treatment decreases the risk of acquiring HIV transmission from our patients. In addition, I would like to emphasise that babies have a high risk of contracting HIV infection from their mother (if she is HIV positive). We need to undertake special caesarean surgery and treatments for HIV-positive (pregnant) women to reduce the risk of HIV transmission from the mothers to their babies.
>
> It is important for us all to participate in the effort to reduce HIV transmission to our children, our future generation.

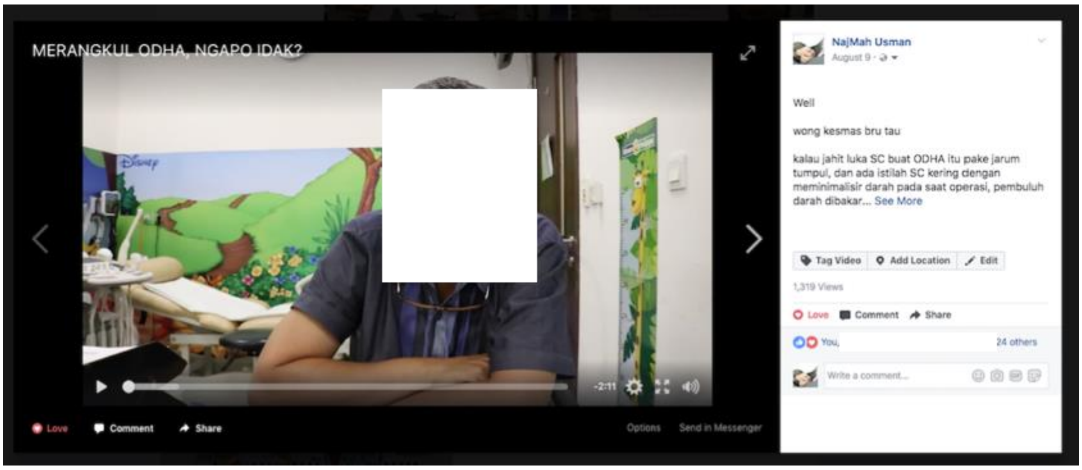
Text-box 7.2: Text for a video to create awareness among health workers of the need to embrace pregnant women living with HIV (Dr Zizi)

(See Appendix D.a.3 for Indonesian version)

Note: Video link (Indonesian version):
https://www.facebook.com/najmah.usman.7/media_set?set=a.10155725665178010&type=3

The video exemplifies how a message from a senior, experienced, and kind-hearted health worker, can contribute to the enhancement of HIV knowledge and practice among health workers, by using social media platforms such as Facebook. Within two weeks of uploading 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)



NajMah Usman
August 9 ·

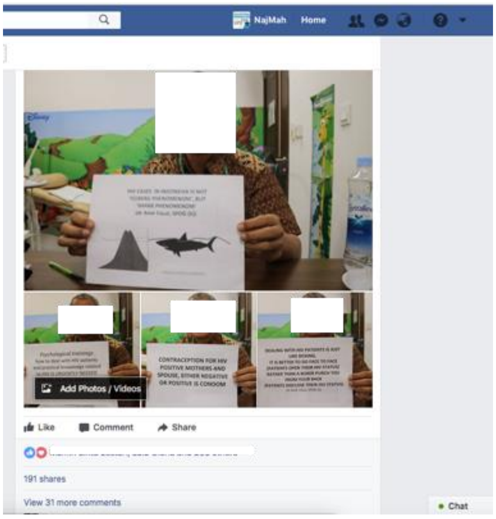
Well

wong kesmas bru tau

kalau jahit luka SC buat ODHA itu pake jarum tumpul, dan ada istilah SC kering dengan meminimalisir darah pada saat operasi, pembuluh darah dibakar... See More

1,319 Views

You, [redacted] 24 others



[redacted]

191 shares

View 31 more comments

Figure 7.7: Video of Dr Zizi, a senior obstetrician, 'going viral' on Facebook

Prior studies have noted the importance of social media, health information, and the role of health professionals (Daniel, Liza, & Jennifer, 2013; Moorhead et al., 2013). Social media can be a powerful tool when used to share health information, enhance the accessibility of information, and influence health policy and public health programmes (Daniel et al., 2013; Moorhead et al., 2013; Ventola, 2014). In contrast to earlier findings, however, no evidence of information dissemination through this video on Facebook endangers the health professional, his privacy, or his health institution, as the content of the video was provided voluntarily by an experienced health care professional related to PMTCT services. I learned how the process of creating this video, and the use of social media for dissemination can incur little or no cost, and even be done voluntarily to enhance HIV awareness among health workers within a global village[66] (e.g. Facebook).

Peer education in partnership with health organisations

The third strategy suggested by a group of midwives, was partnership and networking with health organisations to provide HIV training for health workers in health settings. Insiders were aware of limited funding by the PHO to provide the training on HIV testing, counselling and HIV toolkits (a standard HIV test used in *puskesmas* known as the 'rapid test'). This group of 11 midwives suggested that Palembang PHO should be more proactive in finding organisations that have the capacity to offer training, such as the Midwife Association (*Ikatan Bidan Indonesia [IBI]),* the Nurse Association (*Persatuan Perawat Nasional Indonesia* [PPNI]), and HIV counsellor and VCT associations (*Persatuan Konselor HIV dan VCT Indonesia* [PKHVI]). Furthermore, to engage health workers in HIV programmes, particularly midwives, the principle of shared responsibility to protect themselves as well as protect the babies from HIV, was a necessary key message to enhance health literacy among health workers (see Text-box *7.3*, Ya-Saman lyrics, verse 1). The group was confident that if there were proper counselling training for midwives, midwives would be able to exercise professionalism with appropriate knowledge and skills to embrace HIV-pregnant clients and prevent breaches of HIV patients' confidentiality. The midwives' aspiration was delivered through a song entitled

---

[66] "The world viewed as a community in which distance and isolation have been dramatically reduced by electronic media (such as television and the Internet)" (Merriam-Webster, 2019).

Inilah Suara Bidan Wong Kito Galo (The voice from Palembang midwives' hearts), adapted from Palembang's traditional folk song, "*Ya-Saman*".

Chorus
Ya ya ya counsellor who have been trained [with HIV programme]
Ya ya ya counsellor, please share your knowledge
Ya ya ya counsellor, to every midwife
Ya ya ya counselling, in puskesmas and hospitals

Verse 1
For counsellor, if we have problems
HIV training should be given to us all
Midwives don't know how to do a HIV test
Please, give solutions as soon as possible
So we can protect ourselves
And deliver a baby free from HIV

Ya ya ya midwives who have been trained
Ya ya ya midwives, please give us counselling
So mothers and babies are safe from HIV

Verse 2
For those public health officers, midwife associations, and HIV counselling associations in Palembang
Let's cooperate with us your private midwives
Show us (how) to undergo (undertake) an early HIV screening

Chorus
Ya ya ya saman, please, listen to our hearts
Ya ya ya saman, please make it happen

(Adapted from Palembang's traditional folk song "Ya-Saman[67]")

Text-box 7.3: *Inilah Suara Bidan Wong Kito Galo*

(See Appendix D.a.4 for Indonesian version)

<u>Confidential phone line for constructive feedback</u>

The fourth strategy suggested by a group of HIV-positive women was the need to provide a way to receive constructive feedback to health care providers from patients with HIV. The

---

[67] *Saman* is known as the dance of a thousand hands, and one of the most popular dances in Indonesia. The dance originated from the Gayo ethnic group and spread across different provinces such as Sumatera and Aceh. It differs from *Ya-saman*, a Palembang folk song. The *Ya-saman* folksong is usually sung in Palembang by a man looking for a wife with certain criteria - a good wife, similar to her husband.

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

In this section, the community and social sphere, strategies to create a comfort zone in health settings to empower women to access PMTCT services were explored. Supportive environments in healthcare settings can be improved by focusing on capacity building of health workers' interpersonal relationships and by enhancing awareness of the principle of the shared responsibility for developing professionalism amongst health workers treating HIV-positive patients. The principle of shared responsibility means that treating HIV patients with care can save more children from contracting HIV transmission, and at the same time, protect health workers from HIV transmission, by using proper precautions. In addition, with limited resource funding for PMTCT services, insiders aspired to engage other health organisations to work with PHOs to provide training for midwives. The grassroot healthcare providers for caring for pregnant women in the general population in Indonesia aspired to create interactive education through online platforms, and to activate peer education from trained health workers to untrained health workers in dealing with patients with HIV on a daily basis in healthcare services.

5. What government needs to do to enable women to access PMTCT services

Within the public policy and gender norms sphere, the Indonesian government, particularly the Indonesian MoH, needs to implement guidelines, policies, and regulations as direct political actions to create supportive environments for women accessing PMTCT services. In this respect, participants outlined four strategies to enhance the accessibility of HIV care, particularly for women of childbearing age and HIV-positive women. The first strategy was to use everyday language to promote HIV awareness for women in the general population, and the second strategy was for midwives to take a key role in antenatal HIV testing. The third strategy was to make compulsory HIV testing in health settings confidential and private, and the fourth strategy was to reduce the red-tape for accessing PMTCT services, particularly for newly HIV-infected pregnant women. I start with a strategy focusing on improving HIV health literacy by using everyday language.

Simple language: "Let's protect mothers, children, and health workers from HIV"

HIV information seems hidden for people in the general population who access health settings. Women of childbearing age, without adequate HIV information, may not be offered the test or may be too ashamed to ask for it. Consequently, "how can we get healthy from head to toes, if 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 keluargo 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. PKK[68]), 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.

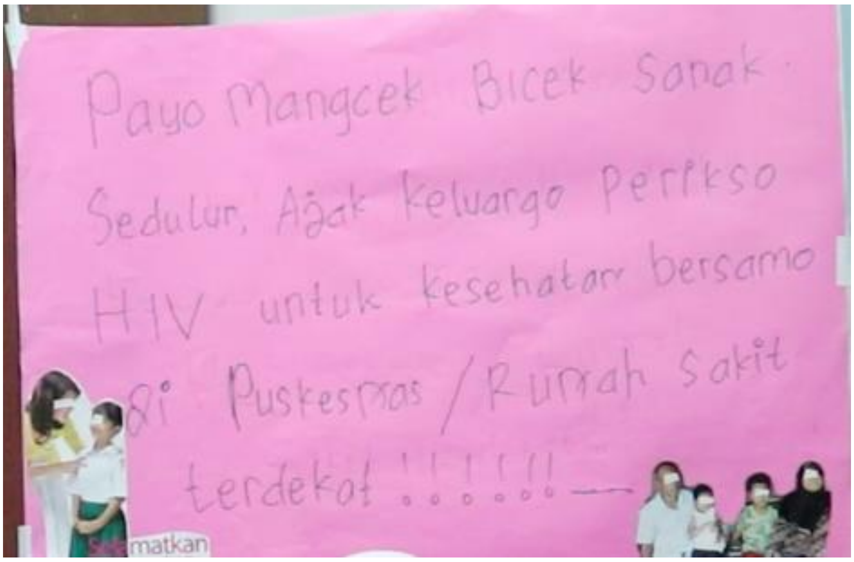


Figure 7.10: Health Promotion poster by Sehati A (six HIV-positive women)

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

Midwives play a key role

To improve the access to PMTCT, government focus is needed on midwives' roles in HIV testing. The participants believed that a midwife should both offer the HIV test and engage and accompany the patient to the closest *puskesmas* for the test. This falls within the realm of "3M" which stands for *menawarkan* (offer), *mengajak* (engage), and *menemani* (accompany). Participants believed that every mother wants her children free of HIV, expressing this as "come on, midwives, offer me an HIV test, so my child will be healthy" (see Chapter 7, verse 3, *Cuk Ma Ilang*).

I asked the group of HIV-positive women, "why should midwives be given such an important role in antenatal HIV testing?" They explained that private midwifery practices (*praktek bidan swasta)* can be found in all urban and rural communities and at the village and sub-village levels. Local and private midwifery services are affordable and have flexible opening hours, as midwives usually practise from their own homes. In 2013, 282 out of 323 (60%) pregnant women in South Sumatera province visited local midwives for their antenatal care, delivery, and postpartum care (Statistics Indonesia, National Population and Family Planning Board, MOH, & Measure DHS ICF International, 2013). Midwives can also be called upon in emergency services to visit patients in their homes outside office hours. Midwives are usually well known and respected by the locals and have lived in the community for some years.

A partnership between local midwives and health workers within PMTCT programmes in *puskesmas* and hospitals may contribute towards normalising HIV testing in the general population, as well as enhance early diagnosis of HIV among pregnant women at an early stage in the pregnancy and uptake of comprehensive PMTCT services for newly HIV-infected women. Within Indonesia's fragmented health system, strengthening midwives' role in HIV screening should be supported with further counselling training (see section on Peer education in partnership with health organisations). Interconnection of both strategies (regulating midwives as a key role, and training midwives in partnership with health organisations) (see previous section) should aim to avoid a breach of patients' confidentiality and enhance the professionalism of midwives. Many HIV-positive women live close to a midwife's private practice; therefore, maintaining confidentiality is important to ensure the wider community is not privy to the midwife's information about patients.

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, *puskesmas*, 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 unhapiness 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.

I am five months pregnant
Visit the hospital to check my pregnancy
After a blood test, I am HIV-positive

I am confused, I am sad, I am scared
What should I do?
A peer support came to me
Telling me all about PMTCT
But I need some referral to the PMTCT services
The referral process made me tired and frustrated
From the hospital to the PMTCT
… to the delivery process
Choosing between having a natural birth or caesarean
Not to mention the prophylaxis treatment for my baby
My baby is healthy and HIV free

Text-box 7.6: I am HIV positive and pregnant

Note: Adapted from an Indonesian popular song or dangdut titled *Putri Panggung* (I am a princess on the stage), created by a group of four NGO workers (See Appendix D.a.6 for Indonesian version).

6. Summary: Intersecting strategies to enhance access to PMTCT services

There is an undeniable need to address the intersection of overlapping individual, relationship, community, and policy spheres to enable women to access PMTCT services (Figure *7.11*). This chapter presented the multifaceted strategies necessary to overcome the challenges that HIV pregnant Indonesian women face in accessing comprehensive PMTCT services. Within Indonesia's unintegrated health system, and in line with a passive approach by healthcare professionals, the present study demonstrates that women need four strategies in each sphere to enable them to access PMTCT services. For example, women need to: 1) know their HIV status by undergoing antenatal HIV testing (Sphere-Public Policies and Gender Norms); 2) strengthen their agency to be resourceful and resilient enough to access PMTCT services (Sphere-Individual); 3) disclose their HIV status to their husband (Sphere-Relationship); and 4) access a hospital with a supportive environment with non-discriminatory practices (Sphere-Community/Social). Thus, early diagnosis of HIV among pregnant women can be detected, followed by early prevention and treatment to eliminate mother-to-child transmission of HIV. Furthermore, implementing such strategies will ensure children who have been diagnosed with HIV get proper ARV therapy, and both women and children get their right to live healthily.

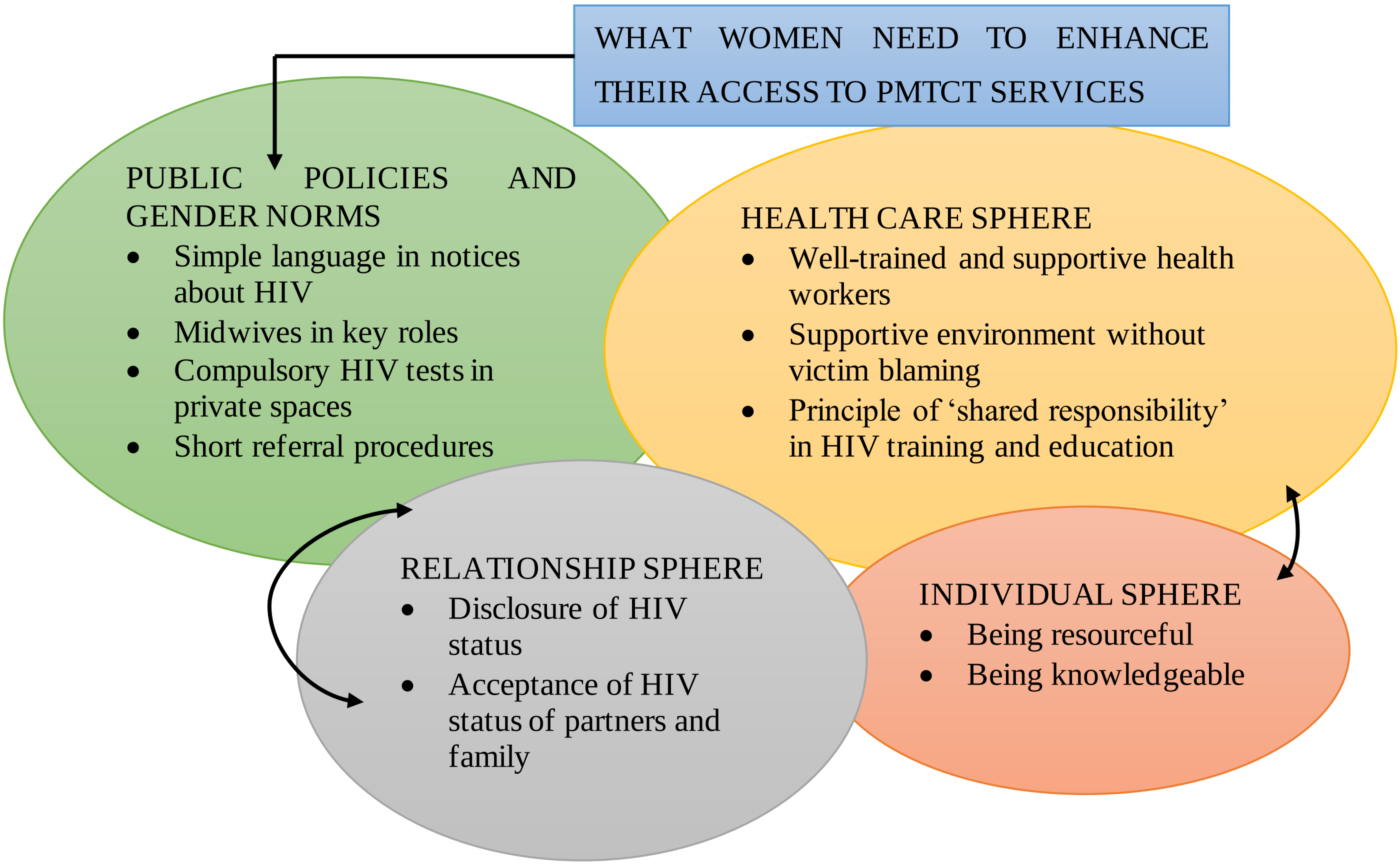


Figure 7.11: Four spheres of the elements needed to support women's rights to access PMTCT services

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 and unclear regulation in health settings

The Ministry of Health's regulations related to HIV testing among pregnant women in Indonesia highlight a woman's role to engage her husband to ensure access to PMTCT services (MoH, 2017a; 2014d). Article 8, point 3, in MoH regulation number 52 in 2017 stated that elimination of HIV among women and babies is urgently needed by enhancing knowledge about HIV and responsibilities among pregnant women, breastfeeding women, sexual partners, family, and society (MoH, 2017a). Yet, other articles emphasised if the woman is diagnosed HIV-positive, the surveillances and treatment focus only on pregnant women with HIV, syphilis, and Hepatitis B with their babies only, not their partners. The explanation for this regulation that the engagement of women's partners or husbands relies on a patient's initiative and motivation or "*ajakan agar pasangan juga diperiksa HIV, Sifilis, dan Hepatitis B"*. The regulation of MoH number 74 in 2014 added that, if the results show negative- or positive-HIV, the woman's responsibility to share or not to share her HIV status and whether to pursue her partner for an HIV test (MoH, 2014d)[71].

I argue for leaving this responsibility to an individual patient. It is counterproductive to the national effort to halt HIV transmission in Indonesia. Further, this endorses cultural norms of 'victim-blaming'. For instance, when an HIV positive woman failed to pursue her partner for an HIV test and treatment, the woman was responsible for her being infected with HIV by her husband (Busza et al., 2012; Lin et al, 2007; Lumbantoruan et al., 2018; Sangaramoorthy, Jamison & Dyer, 2017). Linda Bennett (2015) notes the same observation on fears faced by health providers in offering STIs or HIV test to a woman's husband in infertility clinics. I suggest for the key role of health workers in covering up a partner's HIV status as an active act of deception. For example, health workers may not offer HIV test to a woman's partner and vice versa, hiding a husband's HIV status from her partner or vice versa, due to fears of losing their practice. This phenomenon warrants further study.

---

[71] The explanation for counselling process for pregnant women who access HIV tests, if the result is negative or positive, the regulation stated that "*anjuran koselling dan edukasi kepada pasangan agar melakukan tes HIV*" or a suggestion to counselling and education for the partners to perform HIV test during a counselling process with the women (MoH, 2014, p.34).

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 homosexual practice and deception in marriage in the Indonesian context (McNally & Grierson, 2015; Morineau et al., 2011).

Marital deception and non-consentual sex

One of the main factors that contributes to women's vulnerability to HIV infections is the practice of non-consenual sex, combined with low condom use across the marital continuum. Within this heterosexual hegemony, husbands and wives may have different status and decision-making power in marriage and sexual relationships. The government and popular interpretations of Islamic law and local culture frame the primary obligation of wives to obey their husbands and not challenging a husband's authority (Nurmila, 2016; White & Anshor, 2008). There is also male pre-assumption of sexual entitlement within marriage that both reflects and "reinforces broader cultural construction of gender inequality" (Idrus & Bennett, 2003, p. 41). Of note here, 17 of 18 HIV positive women in this study were of Muslim background. Therefore, a woman is not expected to enquire about her husband's past sexual behaviour nor to refuse any sexual request from her husband (Bennett, 2007; Idrus & Bennett, 2003; Nurmila, 2016). However, all participants in this study were not using condoms before knowing their HIV status. Of course, if one partner is positive, another partner is at risk to contract HIV (Pisani, 2010; Praptoraharjo et al., 2016a; Riono & Jazant, 2004). The present study suggests women's vulnerability to HIV occurs across marital deception and HIV transmission; hence solutions should be addressed across this marital continuum despite women's marital status.

To sum up the concept of marital deception, I suggest that while the ideal presentation of a marriage is one filled with happiness, love, care, fidelity, and honesty and being monogamous, the reality is different to some extent. The experiences of HIV positive women in this study, and anecdotes from health workers and communities, revealed the 'secret' stories of a marriage, including deceptions, falsehood, manipulation, and lies. Findings from this study concur Jennifer S. Hirsch et al.'s study (2009) in five countries (Mexico, Uganda, Nigeria, Papua New Guinea, and Vietnam), which suggests that extramarital relations may put wives who are monogamous and do not participate in marital deceit at greater risk of contracting HIV (Hirsch et al., 2009). This study extends Hirsch's study (2009), which identified that within a marital continuum, women (and some men) may be at risk of HIV if one of the relational partners has been infected with HIV in Indonesia, and that dominant Muslim cultures and norms do not necessarily support the discussion of this aspect.

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; Ponic, 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.

Women's economic dependency on husband

Poor women are particularly vulnerable to HIV. Wealthy women are also vulnerable to HIV, but they have more options for accessing treatment and care. All participants were economically dependent on their husbands when they were in a matrimonial relationship, but some of them also earned additional incomes for supporting their husbands and family (see Table 4.1, Chapter 4).

Economically independent women, such as those who owned a *warung* or a small bric a brac shop or worked outside the house, had more decision-making power to access HIV tests and services compared to those who were economically dependent on their husbands (Hampada, 2012; Lumbantoruan et al., 2018). Those who were economically independent were more likely to be able to get tested and more likely to determine if the women wanted to access the PMTCT services than those who were not (Hampanda, 2012; Hlartaithe, Grede, de Pee, & Bloem, 2014; Lumbantoruan, et al., 2018). In a few cases, however, a woman who was economically independent of her husband was perceived as having an inferior status in marriage and within her wider in-laws' family. Having a husband meant they had money for medication, but it also meant they needed their husband's permission to visit PMTCT services (Hlartaithe et al., 2014; Lumbantoruan et al., 2018; Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008). Hence, involving husbands in accessing PMTCT services is urgently required in the Indonesian context.

HIV-positive women, therefore, need to be well-informed about PMTCT and succeeded in engaging their husbands to be well-informed about their rights to have HIV-free children for both HIV-positive mothers and their HIV-positive children. Previous studies emphasised that the women, with husband's support, were also more likely to be resilient to access PMTCT services than married women that might have had lack of husband's support (Badriah, Tahangnacca, Alkaff, Abe, & Hanifah, 2018; Hlartaithe et al., 2014; Lumbantoruan et al., 2018; Nguyen, Oosterhoff, Ngoc, et al., 2008). The current study suggests HIV-positive women, if they are well-informed despite their economic dependency to her husband, can protect their health and their babies without facing condemnation and blame. In a strong patriarchal culture, PMTCT services need to provide women's right to information and women's right to informed decision making. Women need to bravely educate themselves and their husbands and involve their husbands to make the family's decision to access to the services, including HIV test and plan pregnancy through PMTCT services.

Education's level of women and HIV literacy

A women's level of education does not guarantee protection against HIV transmission among married women. Of note here, two of the 18 participants had a tertiary education background, twelve out of the 18 participants had completed high-school level (12 years of schooling), and the rest graduated in elementary or secondary schools. The current study shows that the HIV-positive women have differences in women's vulnerability, with multiple intersections of elements related to education and HIV literacy.

Women had a lack of HIV literacy, regardless of their education level, and perceived themselves as at low risk of getting infected with HIV. Interestingly, after being diagnosed with HIV, HIV literacy became one factor for women to be more likely to access PMTCT services despite their education background. With enough understanding of HIV, one out of 18 HIV-positive women from middle-income family sought HIV tests during pregnancy. Others, from low-to high-income families and any level of education backgrounds, learned about their HIV status after they were diagnosis of HIV and enable them to access comprehensive PMTCT services for themselves and their families (Hidayana & Tenni, 2015; Lumbantorun et al., 2018). Additional supports from health workers and NGO workers, such as stigma-free care, may also contribute to supportive environment in dealing with red-tape referral procedure of PMTCT services (Hidayana & Tenni, 2015; Lumbantorun et al., 2018).

A lack of HIV literacy, nevertheless, may disempower women not only to maintain their health, but also their family's health. Women with less education as well as with economic dependence on their husband's income were less likely to be able to get tested HIV at a very early stage after their husbands have been diagnosed HIV-positive (Butt, 2015; Hidayana & Tenni, 2015; Lumbantoruan et al., 2018). For instance, the current study highlights 13 HIV-positive women knew their HIV status only after their husband's sickness or death or their children's sickness or death (Imelda, 2014; Ismail, 2018). The husband's family, such as mother's in law, brother's in-law who may have been informed HIV status of their husbands in health settings; but they chose not to disclose HIV status of her husband to the women (wives) [read Bulan's story in Najmah, Davies, and Andajani (2020)].

Additionally, lack of HIV literacy may result in the misconception of HIV and prevent HIV-positive women access PMTCT services. One instance is that one of 18-HIV-positive women decided not to access ARV therapy and passed away one year after my field research. Having outsider status (for example being a widow or divorcee) and coming from a low-income family 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 occurrs within a marriage (Anindita & Shaluhiyah, 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 & Shaluhiyah, 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 & Shaluhiyah, 2016; Hampanda, 2012; Hollen, 2007; Liamputtong & Niphattra

Haritavorn, 2014). Additionally, with the inability for the wife to independently make decisions on her health, the effectiveness of HIV notification in Indonesian context is warrant for further study. More discussion on marital status is noted in the first section in this chapter on marital deception.

The notion of motherhood

The notion of motherhood is cultural and religious norms of Indonesian mothers, including HIV-positive women. While maternal responsibility may not protect women from HIV infection, it may enhance women's motivation to protect their family from HIV transmission. My research shows that the notion of motherhood enables women to access PMTCT service, despite their education level, economic level, HIV literacy and HIV's disclosure to their husbands. The societal expectation of women in Indonesia as a 'good' mother requires to protect her child's health from any diseases, including HIV transmission. These expectation was mentioned by all participants in my study as their aspiration for motherhood "five years living with HIV and surviving for the kids" (Figure 8.1). This notion supported by religious interpretation of "Paradise lies at the feet of the mother" that means being a mother is the highest social status in Indonesian society despite the HIV status of mothers and children.

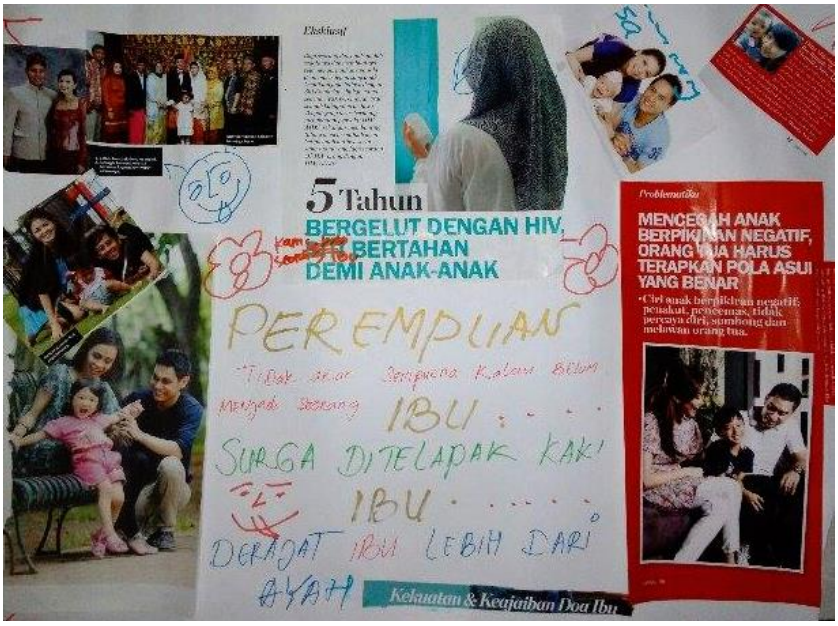


Figure 8.1: Paradise lies at the feet of the mother-Surga ditelapak kaki Ibu (Collage by Sehati A, 6 HIV-positive women)

Note: *Derajat ibu lebih dari ayah*- mother's dignity is over father; *Perempuan-tidak akan sempurna kalau belum menjadi seorang Ibu*-a woman is not perfect if she does not have a child; *5 tahun bergelut dengan HIV dan bertahan demi anak-anak*-5 years living with HIV and surviving for the kids.

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).

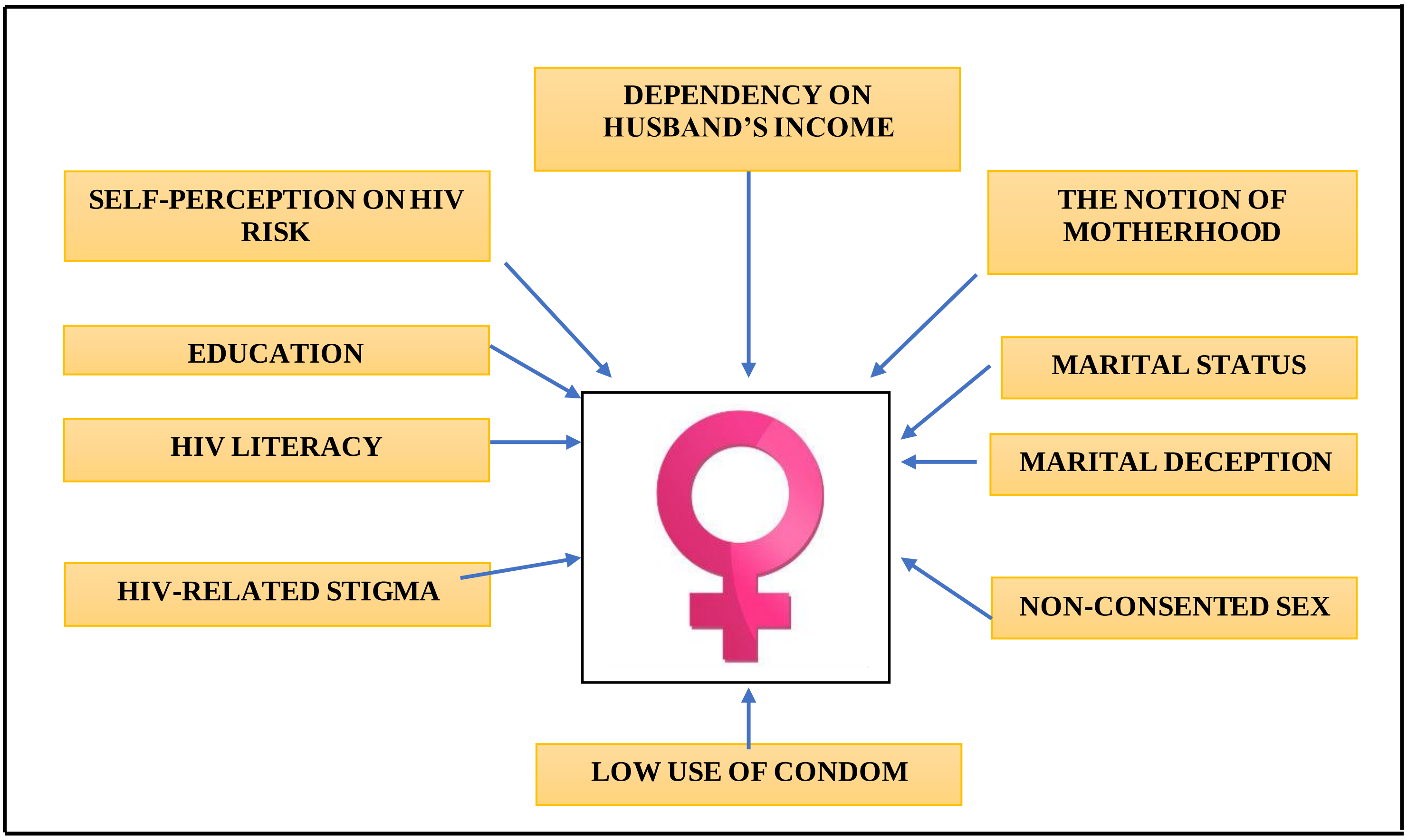


Figure 8.2: Women's vulnerability to HIV infection in Indonesia: An Intersectional approach

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, information barriers, economic barriers and health system barriers that stop women being able to protect themselves and their family from HIV infection.

3. HIV related Stigma in Indonesian Context

"Stigma and discrimination are death penalties; HIV is not" (Mano, 25 years old, a widow with one-negative child).

HIV-related stigma is still rampant in Indonesia. Stigma is "an illuminating excursion into the situation of persons who are unable to conform to standards that society calls normal" (Goffman, 1968). Understanding stigma requires consideration of the intersectional influences of the broader social, cultural, and economic factors that structure stigma beyond the level of the individuals (Parker & Aggleton, 2003). I define HIV-related stigma as negative beliefs, feelings and attitudes towards: people living with HIV and their families; people who work with HIV service providers; members of high risk groups (IDUs, female sex worker, men having sex with men); and married women with HIV.

HIV-related stigma happens in different ways. Figure 8.3 below depicts HIV related stigma in the Indonesian context. There is a range of experiences of women of being stigmatised; they are not universal and not even the same between different groups of people in the same culture in Indonesia, including among HIV-positive women and health care workers (HCWs). In the Indonesian context, stigma can be interpreted as shame or *malu* (Davies & Najmah, 2020a; Najmah et.al, 2020). Furthermore, stigma and shame associated with HIV also intersect with other axes of disempowerment HIV-positive women to access PMTCT services, such as marital status and HIV literacy. This interaction speaks to intersectionality, which I explored below.

Understanding stigma from HIV-positive women and health workers

The section acknowledges the different angles to understand stigma between HIV-positive women and health workers. HIV-positive women argue that health workers stigmatised them in a health setting in different ways. Health workers may or may not ask about the sexual histories of a wife and husband. Other health workers may make a moral judgment when a (pregnant) woman tries to access PMTCT service, such as "are you a female sex worker?" (Shinta), or "just tell me ma'am, did you have an affair as your husband is HIV-negative" (Nika). HIV-positive women accessing HIV services are labelled as not 'good', a badly 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).

This current findings suggest further understanding of “who experiences and who perpetuate stigma” within health settings (Stangl et al., 2019, p. 4). HIV-positive women have dealt with pre-existing stigma and being shameful on their own HIV status (Butt, 2011, 2015; Butt et al., 2017; Stangl et al., 2019). On the other hand, health workers and their stigmatising behaviours against women went beyond individual and interpersonal levels to a wider social, cultural, and structural level. According to Mahajan et al. (2008), Thompson (2012) and Stangl et al. (2019), they outline patterns of behaviour, language, and assumptions towards HIV-positive women that are institutionalised in wider population, including health settings and society. However, I suggest the labelling of HCW towards HIV-positive women makes the women, as a mother and a pregnant woman, lose her status as a ‘good’ mother and wife who sought PMTCT to protect babies from HIV infections and feeling shameful (*dipermalukan)* in a public sphere, such as *puskesmas* and hospitals (Najmah et al, 2020; Davies & Najmah, 2020a, 2020b).

In summary, this study provides additional understanding of HIV-related stigma at the institutional level as a general way of acting within PMTCT services. I observed from my study, arguments presented on the normalisation of ‘institutionalised discrimination’, that vary from justification of fears, taboo sex talk about sexual history of a husband, insufficient knowledge and training in HIV prevention and treatment, to the confusion of differentiating between personal sensitive manners versus good professional conduct. A lack of the availability of universal protection supplies in health setting further reinforce reluctance of HCWs to treat HIV-positive women. Hence, enhancing the empowerment and capacity of HIV-positive women in responding to stigma, and providing strategies to increase the willingness of healthcare providers to treat women, are urgently needed and must be informed by women themselves and HCWs, as well as by prevailing social and cultural norms and values.

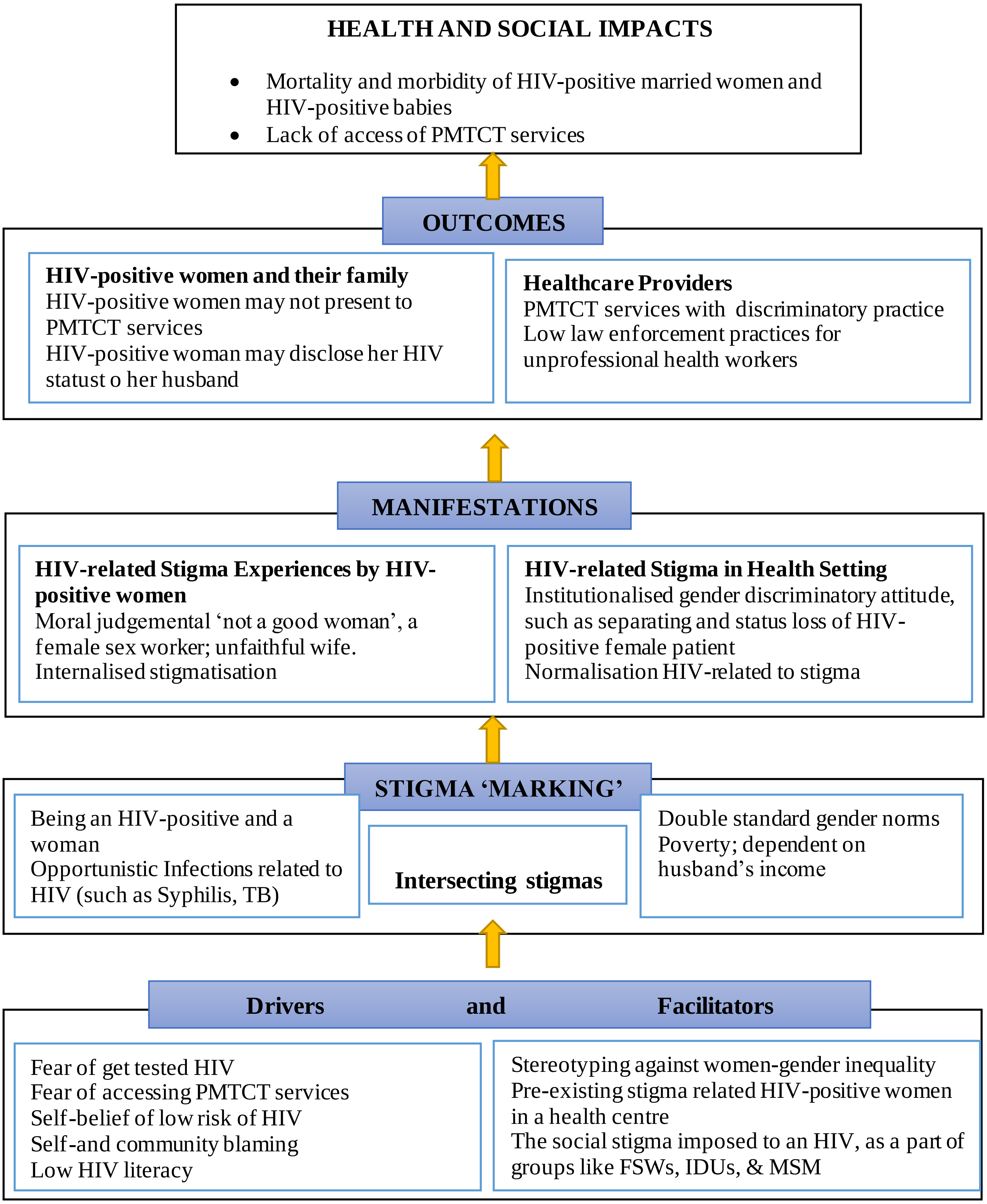


Figure 8.3: HIV-related stigma in Indonesian context (adopted from Stangl et al., 2019)

Intersectional stigma and HIV vulnerability

The second sub-section discusses intersectionality on HIV-related to stigma. Elements of age, economic and social status, marital status, religions, location, in addition to her HIV status may all impact on the type and extent of the stigma they face internally or externally. Every woman in this study has different intersections that make them vulnerable to HIV, as discussed in the second section of this chapter. The difference of marital status, double standard, gender, dependency on a husband's income and age of HIV-positive women appear to intersect with HIV-related to stigma and disempower or empower the women to claim their rights to access PMTCT services.

Women, with multiple intersecting stigma (Figure 8.3), may contribute to a cumulative effect on HIV-related stigma and women's vulnerability to their access to PMTCT services (see Figure 9.3). For example, Mano (participant no 9, Table 4.1 in Chapter 4) was 23 years old when her husband died due to opportunistic infections related to AIDS. The couple had a HIV negative boy. They were poor, living in shack house by the city swamp in one of the slum areas in Palembang. Mano made a very insightful comment that "stigma and discrimination are death penalties; HIV is not" (Mano). She repeated this statement during several of my encounters with her. She describes the social stigma imposed on an HIV positive woman as physically and mentally denigrating, socially victimising and distancing. By having the HIV status, she felt socially rejected, undesirable, shameful and depressed. She refused any treatment or programme offered. She belonged to an online social group that is denied their HIV status and rejected ARV treatment. This group called themselves as *Masyarakat Anti HIV/AIDS dan Sehat Tanpa ARV* (Maha-Star) or society who disbelieves HIV/AIDS and keeps healthy without ARV[72]. She also opted for traditional or alternative therapy. Her health deteriorated very fast; she acquired opportunistic infections, like Tuberculosis and Herpes, and died within less than four years after being diagnosed with HIV.

Following her death, which was one year after I completed my fieldwork, I received many communications from my participants' networks who mostly access ARV therapy, expressing sadness and anger. They were all in disbelief and were regretful that Mano refused any help and assistance they had offered to her. Mano's story may reflect the notion of self-imposed

---

[72] link: Maha Star in https://www.youtube.com/watch?v=mOIIkT_rih8&feature=youtu.be

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 (Hampanda, 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 good wife and mother. In Indonesia, dominant Islamic and cultural perceptions of a wife and women (as per the biblical and Koranic stories of Eve) are constructed in a way as to require more from women to uphold the moral virtues in a family (Ayubi, 2019). This may contribute to internalise stigma related to gender inequality (Ayubi, 2019).

Furthermore, this normalisation of institutionalised gender discriminatory practices occurs in health settings, as well as in marriage, thereby burdening women diagnosed with HIV. Thus, it becomes hard to increase health-care accessibility against the constraints of gendered morality within social, cultural, moral and policy norms, especially among *ibu rumah tangga*. The question that arises, is how to deal with this challenge and enable women to access PMTCT services. One answer is the need for the normalisation of empowerment of women and the inclusion of women's voices, as well health workers' voices, to re-orient PMTCT non-discriminatory provision of care and services to contribute to assuring WLWH have the right to access PMTCT (see Chapter 9).

My findings raise an intriguing question that how different the situation might have been for an HIV-positive woman with an HIV-positive baby. If she had been offered an HIV test by her local, private midwife during her pregnancy, she would have been advised to have a caesarean birth and use formula feeding to eliminate HIV risk to her baby, her (now) HIV-positive daughter. If she had been able to perceive herself as a good wife and mother, she might have sought an HIV test after knowing of her husband's extramarital relationship. If health workers understand health issues in the social context, after knowing about marital deception they must protect female patients emotionally and physically as being a faithful wife and husband. Health workers may provide a space for a wife and a husband to share their personal vulnerability to HIV and provide better service for the whole family. If the doctors treating HIV-positive women's husband had informed them that they and their children were also at risk of HIV and that they needed to get tested as soon as possible, the outcomes would have been very different. While some HIV-positive women were able to seek medication in time, the fate of many other women has not been as positive.

4. Reflection

Within the complex story of HIV transmission, the current study found that women need to be aware that all Indonesian women are at risk of HIV even though they are not exposed to high-risk behaviours. Studies on the dynamics of HIV transmission in Asia have been conducted in 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 Jacubowski'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) and other behaviours related to increasing HIV risk. The impact of these cultural norms of marital deception regarding sexual histories, behaviours and identities and consider the impacts on the prevention of HIV risks and what would be needed to actively challenge this norm in Indonesian society with the majority of Muslim worldwide. There is not legal requirement in Public Health Law in Indonesia for men or women to be legally required to declare their HIV status to their partner as is the case in some countries, such as the United Republic of Tanzania, Canada and United Kingdom (WHO, 2016).

By acknowledging that *ibu rumah tangga* are complex beings living in complicated social worlds, awareness campaigns and treatment programmes related to PMTCT can be targeted towards them. Indonesian women need to be aware that pregnant women are categorised as risky groups for HIV infection, and they have rights to HIV tests at their closest *puskesmas*. If women find out early that they have HIV, they can start medication and implement practices to decrease their chance of transmitting HIV, especially to their offspring. As a result, acknowledging their risk and empowering women to get tested and seek treatment will help curb HIV transmission rates.

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-making, and experiences of HIV-positive women, and at times, of their families, and health care providers in accessing HIV services. They can also provide intersected solutions for enabling women to access PMTCT services.

This chapter is closely linked to chapter 3 (PMTCT: A global and Indonesian context), chapter 4 (Methodology), and chapter 7 (What women need to enhance their access to PMTCT services). Three sections in this chapter include: 1) The four-pronged approach to PMTCT policies and practices; 2) Methodological implications of Feminist of Participatory Action Research; and 3) Study limitations. I conclude this chapter with a personal closing statement.

1. PMTCT policies and practices based on four prongs

A comprehensive and intersectional approach to improve the accessibility of PMTCT services would benefit Indonesian women in particular and society in general. My findings confirm the importance of the application of a holistic approach which can be integrated across different key stakeholders, including HIV-positive women, public health offices (PHO) and health professionals, NGO workers, and provincial and central government level.

The following Table 9.1 highlights relevant the study findings that can easily be adopted in existing PMTCT services in Palembang, the study setting, and potentially at the national level. This table summarises key recommendations made by my participants, which include: integrated maternal health and PMTCT services. For example, the promotion of HIV knowledge, respect for women’s rights to health; the roles of midwives in PMTCT programmes; and the development of relevant training, supervision, monitoring, and respectful attitudes and professional skills amongst health workers when working with HIV positive women and their family.

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	• IEC is expert driven • The use of loaded and judgemental language is counterproductive which promote victim blaming	1. The use of simple, locally relevant and non-judgemental languages for IEC ○ 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

2. Preventing unintended pregnancies among HIV-positive women	Family planning	• Lack of promotion of safe sex and condoms use • Family planning programmes rarely catering or targeting HIV positive women in Palembang	1. Condom promotion in marriage couples 2. Family planning clinic in PMTCT services	6, 7
3. Preventing HIV transmission from a HIV-positive woman to her unborn baby	HIV testing & VCT Antenatal care access for HIV-positive pregnant women	• HIV test in pregnancy is not consistently offered to all women • Limited access to HIV test • Normalisation of HIV-related stigma in health settings, making health workers feeling fearful to offer HIV test	1. Midwives as a central role in promoting HIV test for pregnant women 2. Rights-based training for health professionals on universal health access	3, 6, 7
4. Providing appropriate treatment, care, and support to mother living with HIV, and their children and families	HIV-positive mothers' friendly space	• Current policies and programmes that continue to endorse the normalisation of HIV-related stigma in family and health setting	1. A dedicated women's friendly service in PMTCT services with consultation/supports for HIV positive women and family as well as with HIV strengthening health service delivery.	3, 6, 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-judgemental 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

HIV test in local *puskesmas* or hospital' (read Conn et. al. 2017, Lubis, 2018, and Maibvisira, 2018). These recommended messages produced by my participants were somehow contrasting with existing messages which used 'loaded words', such as "Avoiding HIV-AIDS by being faithful to a family" (Chapter 7).

Figure 9.1 HIV test is not scary (see Cuk Ma Ilang modified lyrics, in Chapter 7)

Prong 1 - recommendation 2: Using social media

The development of IEC materials need to involve women and relevant social media which can be easily accessed by the community, especially by women. All participants, health providers and NGO workers in this study, owned smartphones or android. Given the significant growth in cheap and accessible internet in Indonesia, women, like my study participants, would be in a better position to proactively learn, share, and create sexual health knowledge through online media, such as Facebook. Study participants were excited when they posted their HIV campaigning messages and have them shared it on their community Facebook page and YouTube. This recommendation on the use of social media in the promotion of sexual health and HIV prevention is well-aligned with studies by others (Conn, Nayar, Lubis, Maibvisira, & Modderman, 2017; Daniel, Liza, & Jennifer, 2013; Lubis, 2018; Moorhead et al., 2013).

Prong 1 - recommendation 3: Endorsing a transformative change in communicating the PMTCT programme to the grassroots.

Partnership for responsive transformative change is central for effective health promotion programmes (Gaventa & Cornwall, 2008), including generalizing or normalising HIV testing in pregnant women. My findings showed that there were different collective learning spaces amongst HIV positive women and family, NGO workers and volunteers, 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.

Prong 2: Plan of action for prevention of unintended pregnancies among HIV-positive women

Prong 2 focuses on the prevention of unintended pregnancies in HIV positive women. Services within Prong 2 may include family planning counselling and services for HIV positive women and partners/husbands. Contraceptive use and HIV positive women were not the focus of my research. However, women brought conversations on contraceptives or family planning to some extent. None of the 18 HIV-positive women in this study were using condoms before knowing their HIV status. Only after knowing their HIV status, only four of 12 HIV-positive participants who were living with their husband, decided to use condoms. The rest, eight of them, opted for injectable, or IUD, or implant, or using no contraceptive.

My findings confirm other studies that found condom use among married couples as low as 4 % (MoH, 2013b; Praptoraharjo, Suharni, Pudhiati, Dewi, & Safika, 2016). The fantasy of marriage as sacred and holy, monogamous, and being a loyal partner, to some extent, may hinder the use of condoms in marriage. A partner asking for using condoms may be met with a suspicious attitude by the other partner. When pre-marital sex is widely and socially condemned, marriage in Indonesia could be seen as formal approval for couples to have sex. Non-consentual sex is not expected in married couples (Bennett, 2005; Idrus & Bennett, 2003). The idealization of the institution of marriage as loyal and faithful, endorsed by many religious teachings and cultural norms, may add the illusion of sex in marriage as a safe practice, as noted in studies in Indonesia (Jacubowski, 2008) and Mexico, Uganda, Nigeria, Papua New Guinea and Vietnam (Hirsch et al., 2009).

This illusion of safe sex in a heterosexual marriage, as a default, is somehow counterproductive to the effective promotion of condoms use in married couples. At the same time, condoms promotion in Indonesia is often condemned as promoting infidelity and sexual delinquency practices and are often opposed by society at large (Praptoraharjo et al., 2016). Unlike family planning practice in Australia and New Zealand, where I observed that free condoms are offered on a regular basis, family planning in antenatal clinics in Indonesia rarely or even never offer free condoms or prescribed monthly condoms and using condoms depend on women’s reproductive agency (Praptoraharjo et al., 2016; Spagnoletti, Bennett, Kermode, & Wilopo, 2019). Integrated family planning 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 midwives[73]. 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).

Sumatra at the time of my fieldwork (Chapter 6)[74]. Pregnant women who did not access *puskesmas* or hospital for their antenatal care visit may not be offered HIV tests (Badriah et al., 2018; Wulandari et al., 2019).

- Second, women were fearful to ask for an HIV test due to the HIV stigma attached (Chapter 7).
- Third, heterosexually married women did not see themselves as being vulnerable to HIV infection (Chapter 5).
- Fourth, when a woman was proactively asking for an HIV test, her request might be denied by her health providers and she might have been asked to seek permission from her husband (Chapter 6). Of note, no regulations require a woman to seek permission from her husband for HIV testing (MoH, 2014, 2016, 2017).
- Fifth, the culture of the top-down approach is normal in which the HIV training was presented by the trainers, and trainees tend to be passive, according to my observation of participating in HIV training for midwives and other groups of health workers[75].

Midwives who participated in this study were excited about the opportunities for them being at the front frontier to PMTCT programmes. This group of midwives produced and narrated a Ya-Saman traditional song (Chapter 7) to inspire increasing antenatal HIV testing. One message in this song urges for the support that they need to improve HIV testing by a revitalization of relevant HIV training from private midwives. I, therefore, believed that such training could build confidence amongst midwives, as it did not provide opportunities for knowledge sharing nor it was based on strength of partnership-based approach. A strength-based approach, by honoring the voice of midwives through partnership and a variety of creative representations from their expressed aspirations, is

---

[74] Compulsory HIV testing in pregnant women was only made compulsory to be offered after 2013 and compulsory to be tested after 2015 (MoH, 2013a, 2015, 2016, 2017). Compulsory HIV testing in Palembang was implemented in 2017, therefore only three of the18 HIV positive women in my study had done HIV tests in pregnancy. The remaining 15 women had never been offered any HIV tests in pregnancy prior to 2017. The latter group often only knew their HIV status quite late.

[75] Training participants were seated in rows and discouraged from asking questions. The training was conducted in a lectures' type, with very limited time for discussion, debate, and shared experiences. After the session was ended, five midwives came to me and shared their experience to help their HIV-positive clients. (see Chapter 6).

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 *puskesmas* 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

(CEDAW, 1979); the 1994 International Conference on Population and Development Programme of Action (ICPD Cairo PoA) (UN WOMEN, n.d.) and subsequently the Beijing Declaration and Platforms of Actions (1995-2015) (UN WOMEN, n.d.; UNFPA Indonesia, 2014).

Within this digital era, with vast ownership of smartphones and androids, I see the central role of the internet. Any online platforms to promote discussions, share ideas and experiences, discuss. Hence, innovative strategies to deliver a right-based approach to train midwives and other health workers are required with limited funding for HIV trainings for all health workers. From a specialist gynaecologist who participated in my study, I was made aware that a peer-education approach promoting professionalism and respectful attitudes and services to HIV positive women would be worth exploring. For example, Zizi, a gynaecologist, recorded his video and it was uploaded to Facebook and received an overwhelmed responses, such as "very inspired doctor", and "kind-hearted doctor" from his peers, health workers (Chapter 7). As a result, peer education or mentorship programme from senior to junior staff can be a feasible solution to the dearth of training availability and limited funding for human resources, to challenge the social stigma attached to HIV among health workers.

Right-based training for health professionals through peer education, hence, needs to challenge the overgeneralized myth that HIV-positive women are not good mothers. Being HIV-positive women does not diminish the love of a mother to her children and partner. All participants in this study found the motivation to have a healthy family and HIV-free children as the utmost important motivation. Therefore, all participants in this study believed that HIV tests should have been made compulsory for all pregnant women.

Rights-based training for health workers may include the following topics. First is an open and safe space for health professionals to explore issues, attitudes, experiences, and behaviours that would make stigma worse. Second is exploration a digital space or the use of the internet to effectively deliver the right-based care, training, and communication. Third is the digital platforms could be used as a validating mechanism on the importance of a topic proposed and to gather responses (e.g. likes, shares, and watchers). Finally, fourth is a digital survey can be used in tandem with any information and training modules (webinar, etc) for the evaluation of programmes.

Prong 4: Plan for action – providing appropriate treatment, care, and support to mother living with HIV, and their children and families

This section mainly discusses the need for women's friendly space to enable women to access PMTCT services. Prong 4 focuses on treatment and support for mothers and their children living with HIV. Programmes within Prong 4 focus on, for example, the provision of prophylaxis treatment and advice and support on feeding practice for babies born to HIV-positive mothers (MoH, 2015). My research did not focus on HIV positive children. It was expected, however, that some of my participants would have HIV-positive children. I met three HIV positive women raising HIV-positive children and four participants with their babies under prophylaxis treatment and formula feedings. I asked them about their access to prophylaxis and ARV treatment for their children and how it can be improved.

They aspired for women's friendly space in PMTCT services. HIV-positive women in my study desire to have healthy children. They also dreamt of having a prospering family and healthy children. Some participants brought forward the idea of having a specific and women's friendly clinic that especially can cater to the needs and understand the life context of HIV positive women. Services within this proposed special clinic shall include family planning, pregnancy preparation, antenatal care services, childbirth preparation, and raising healthy children.

All of my participants had a good understanding of their needs for ongoing communication and access to PMTCT services. They also realized their needs for some psychological and social supports from health care providers. Therefore, the potential of having integrated family-oriented services for families with HIV-positive family members warrant further studies. However, that a woman's life and wellbeing cannot be separated from the wellbeing of women's families (Nurmila, 2016). Early detection of HIV in couples enhance the possibility for those couples and their offsprings to have a healthy and productive life (Rahmalia et al., 2015).

My findings concur with other similar studies in the Asian context, where women are central to the survival and decision-making mechanism around accessing HIV care in India, Thailand and Indonesia (Hardon, Oosterhoff, Imelda, Anh, & Hidayana, 2009; Hidayana & Tenni, 2015; Hollen, 2007; Liamputtong & Haritavorn, 2014; Lumbantoruan, Kermode, Giyai, Ang, & Kelaher, 2018). My findings also support the need to strengthening health systems and a culture of service delivery that is context relevant and respectful of women's needs and aspiration (Schneider, Blaauw, Gilson, Chabikuli, & Goudge, 2006).

2. Methodological Implications: FPAR as an important methodology to create a safe collective space for HIV positive women

Throughout my research journey, I learned the following principles of FPAR, which were important in the creation of a safe and collective non-discriminatory space in working with HIV-positive women. For example, I learned to be an empathetic and active listener. I learned to listen and made myself aware of my positioning in this research and how my positions changeable between an insider and outsider. I was made acutely aware of the knowledge, experiences that participants brought to my research. They certainly are the 'real knowers' and 'experts' in their life context.

Table 9.2 Principles FPAR working with groups of HIV-positive women

Principle 1	Cultivating trust with marginalised women
Principle 2	Creating a space for non-discriminatory open dialogue with a critical analysis of gender relations
Principle 3	Centering women in a safe physical environment
Principle 4	Honouring the voice women through partnership and varieties of representations in expressing aspirations
Principle 5	Advocating for a quick responsive change
Princple 6	Proposing an intersectionality lens: accomodating the multi-layered, complex socio-cultural and political context of women lives

Note: Adopted from Reid and Frisby (2008) with reflection on my research experience

This second part of this chapter will focus on five principles of FPAR that had been very relevant to my research, as summarised in Table 9.2. I learned that building trust to cultivating partnership, dialogic relationships centering on women's stories, and honouring many forms of action are keys to facilitate critical discussion and research ownership, that will be discussed below.

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 to allow for conscious reflection and to value … their [women's] own diverse strengths and capacities' (p. 161). Through an open dialogue, I learned to see the importance of women local context, such as the notion of family (*kekeluargaan),* gender relations, sexism, gender biases, and discrimination

I employed two strategies to create a space for open and critical dialogue. My first entry to opening a dialogue with my participants was sharing my background of being born and raised in Palembang – as a local - (*wong Palembang*) and speaking the Palembang dialect. I also shared with them my upbringing stories, my marriage, and motherhood and my third pregnancy; I was 4 months pregnant at the time of my research.

Being a local person also helped me to fast learn about local practices and customs. I needed to be aware, however, to not assume that I did understand and knew everything as I was a local. During online supervisory meetings, I was reminded by my supervisors to reflect and think critically on the contexts and stories presented by my participants and encourage participants to be my partners in building the knowledge around gender relationships within their relevant life context. Through this research, I learned that while interpersonal skills are important, as a researcher, I also needed to be a naïve inquirer and active listener. I should always check my understanding with participants in an open and reflective dialogue. These skills helped enhance the credibility of my findings (see Meriam, et.al., 2001).

Second, I created a 'space' that was informal, relaxing, and flexible. For example, we had our family picnic in a local park, where we brought our children to play and fun. This attempt, I believed, had helped to reduce any power imbalances between me and my participants in this research. Reflecting on this strategy, I wonder if it can be translated to what an "empathetic centreless dialogue" as noted by Reid & Frisby, 2008 (p. 98) as a means to create fluid power dynamics between the participants and me. In addition, I was aware of the importance of the notion of family in Indonesian society, therefore the reflection in this value in my research had potentially allowed for more open and centreless dialogue within my research sphere.

The other social custom to strengthen engagement in Indonesian society is about *anjangsana,* which may involve visiting and sharing food and home cooked dishes (Indonesian Dictionary (KBBI), 2020). I visited participants' houses and had lunch with 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. Ponic, 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.

Fourth Principal: Honouring the voice women through partnership and varieties of representations in expressing aspirations

The fourth principle of FPAR is relating to honouring the participants' forms of action, by accepting a variety of creative representations (using visual outcomes) expressing their aspirations, based on the participants' choices. Borrowing Reid and Frisby's (2008) work on honouring many forms of action, my research promotes and honour the production of diverse creative actions made by participants. In this study, I was very open to women's desires either to work on actions as a group or individually. They had full control of any method they decided to use, many opted for visual methods, such as drawing, collage, drama, creation of a song (i.e. Cuk ma Ilang)

Allowing women to decide to work individually or collectively, and later to share their actions with each other, became an effective way of collective aspiration sharing and validation. In Chapter 7, I discussed the reactions and responses from groups of health workers, NGO workers, and policymakers to allow for reflective discussion. In Chapter 7, I also presented actions made by groups of midwives, health workers, and physicians and had shared them with the HIV stakeholders, regional or provincial PHOs. In summary, allowing a safe space for women to own, reflect, and share their lived experiences while at the same time experimenting with visual methods, strengthened women's confidence and ownership of this research.

Fifth Principle: Advocating partnership for responsive transformative change

I was fully guided by women on ideas around partnerships and dissemination of their actions. I consistently asked them: "What should we do next?" Participants wanted their voices and concerns to be heard. One participant told me: "Bu Najmah, don't forget to deliver our voices to PHOs and hospitals' Groups of midwives, NGO workers also asked me to deliver their voices to *Dinas Kesehatan* or PHOs and two hospitals with PMTCT services to help improve access to PMTCT services. For example, a lyric in the song written by a group of midwives: "Please, give solution as soon as possible, so we can protect ourselves and deliver a baby free of HIV" (see Chapter 7). I later learned that connection and partnership with health workers and NGO workers, added further mechanisms to develop appropriate and effective communication strategies for HIV positive women to share their concern, needs, and aspiration. Here, I reflect on relevant notes of Gaventa and Cornwall (2008), who endorse connection and engagement as "a 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.

PENDIDIKAN

6

PALEMBANG POS
RABU 5 DESEMBER 2018

IKA FKM Unsri Galang Donasi 10.000 untuk ADHA

PALEMBANG – HIV Aids tidak hanya menyerang orang-orang tertentu, tetapi ibu rumah tangga bahkan anak-anak pun beresiko terkena HIV Aids karena masih kurangnya pemahaman orang tua tentang cara-cara penularan HIV Aids itu sendiri.

Oleh karena itulah, Ikatan Alumni Fakultas Kesehatan Masyarakat (IKA FKM) Universitas Sriwijaya (Unsri) mencetuskan program gerakan donasi 10.000 untuk Anak Dengan HIV Aids (ADHA). Berlatar belakang dari tanggung jawab moral yang mereka rasakan, IKA FKM Unsri ingin memberikan kontribusi dibidang kesehatan masyarakat meskipun mereka sudah tidak lagi berkecimpung didunia kesehatan.

Saat ditemui, kepada Palembang Pos, Fison Hepiman selaku Ketua IKA FKM Unsri mengungkapkan rasa kerinduan alumni dibidang kesehatan. "Gerakan Donasi 10.000 untuk ADHA ini lahir dari rasa kerinduan untuk berkontribusi didunia kesehatan, nah diantara banyak masalah kesehatan, kami pilihlah salah satu yang kami anggap masih butuh perhatian yaitu masalah ADHA," ungkapnya.

Fison menambahkan jika proses menjalankan program ini juga dibantu oleh komunitas Sriwijaya Plus. "Setelah dipilih dengan berbagai pertimbangan, kami meminta pendapat, saran dan tanggapan dari Sriwijaya Plus dan syukurnya mereka menganggap bahwa masalah ini memang penting karena perhatian untuk ADHA sendiri masih sangat minim," lanjutnya.

Dirinya mengatakan jika program yang digaungkan pemerintah, dalam skala nasional maupun internasional tergolong masih sangat minim. Sehingga IKA FKM Unsri memutuskan untuk melaunching program gerakan donasi 10.000 untuk ADHA. "Program ini kita launching bertepatan dengan seminar nasional dan reuni akbar IKA FKM Unsri tanggal 17 November di Hotel Wyndham Jakabaring Palembang," tuturnya.

Dan sejak di launching, belum sampai satu bulan donasi yang terkumpul melalui Program Gerakan Donasi 10.000 untuk ADHA sudah mencapai 5juta rupiah. "Dan mudah-mudahan program ini bisa berkelanjutan dan dana yang terkumpul juga semakin banyak. Untuk penyaluran donasi ke ADHA sendiri kami akan berkoordinasi dengan pihak Sriwijaya Plus," pungkasnya.

Untuk anak yang ada di provinsi Sumatera Selatan sendiri, Fison mengatakan jika ada sekitar 30 ADHA. "Untuk daerah hampir merata jumlah 30 itu, dan target kedepan kami akan terus sosialisasikan program ini, tidak terbatas di alumni kami tapi juga kesemua lapisan masyarakat. Kami juga akan ikut mengkampanyekan nol diskriminasi. Dan yang berhak menerima donasi ini adalah mereka benar-benar ADHA dan membutuhkan bantuan atau dari keluarga yang tidak mampu," tegasnya.

Menanggapi masalah kurangnya perhatian dari pemerintah, Fison menjelaskan jika semua ini berawal dari kurangnya edukasi terhadap ADHA. "Kalau menurut saya, selama ini yang kita ketahui, mereka yang berkecimpung dibidang ini adalah dari kelompok mereka sendiri artinya kelompok diluar mereka masih minim perhatian. Dan salah satu misi yang kami bawa adalah mengedukasi bahwa ini loh masih ada masalah kesehatan yang butuh perhatian," tukasnya.

Melalui program ini Fison berharap akan ada lagi Ikatan Alumni atau organisasi atau komunitas lain yang mengikuti jejak mereka untuk masalah HIV Aids. "Untuk saat ini kita belum ada target berapa nominal target dari program Gerakan Donasi 10.000 untuk ADHA," tutupnya. **(Str)**

Anggota dari Ikatan Alumni Fakultas Kesehatan Masyarakat Unsri yang tengah mengajak Anak Dengan HIV Aids (ADHA) di kota Palembang Untuk Belajar Menggambar dan Mewarnai.

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 discrimination to help me that explores the tensions that HIV positive women faced in Indonesia. Confirming Reid and Frisby (2008), my participants' existence is always at the intersection of multiple identities, all of which influence one another and together shape their continually changing experience, tensions and interactions with others. Through PFAR, my participants brought a seemingly abstract conception of intersectionality into a real-life story. They helped me to understand their positioning and tensions experienced by taking me to journey into their lives. Hence, their actions and aspirations were produced from their understanding of their life context into a pragmatic action (Bowleg, 2012; Ponic, Reid & Frisby, 2010; Reid, Ponic & Frisby, 2008, Maguire, 1996).

3. Limitations of the study

While the strengths of this study relate to its ability to facilite participation, ownership, and reflective practice in research and the production of actions which readily to be disseminated to relevant stakeholders at various level, this study also have some limitations that relates to the recruitment of participants, study site and information bias.

Participants

1. Participants' recruitment

Women living with HIV (or WLWH) are a hidden population, so I recruited the participants purposively with help from NGOs, health workers, and my research facilitators. This recruitment of participants could have produced biased results as participation might not be truly voluntarily but influenced by previous relationships and connections with NGOs, health workers, and their staff. However, I also provided information sessions individually or collectively to allow prospective participants up to two weeks to decide whether to participate in my research. I also recruited 47 participants who were health workers, NGO workers, and policymakers by sending a formal letter to the leader of each institution. It was possible that participants were chosen by their institutions to participate in my study and that their participation were not voluntarily. However, in my study invitation letter, I attached participants' information form, informed consent and my contact details should any of them had questions to ask prior to their participation.

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.

Additionally, health workers may have withheld information to protect the credibility of their health institution. However, some efforts were undertaken to minimise information bias to increase the credibility of the findings. For example, triangulation with other groups in this study and guidance gathered from the research advisory group was very beneficial.

4. Closing statement

> So, help them be aware, help them talk, and let us listen......
>
> It is just the beginning.
>
> (Najmah, Three Minute Doctoral Final, AUT[76], August 2019)

The above epigraph comes from my presentation in the Three-minute Thesis Competition finals at AUT (Najmah, 2019, 23 August). The epigraph reflects the words of a HIV-positive woman, showing that she knows solutions of her problem. Next I would like to conclude this chapter with my closing statement.

When I started my PhD journey in October 2015, one of the speakers in my PhD orientation reminded all of us: “remember, your research needs to benefit to your community”. I am confident ‘yes’ my research has been benefitting my community. Upon returning to New Zealand to write my thesis, I continued to keep in touch with my research participants and I was well aware that through audio-visual materials, the aspirations and voices of the women continued to travel visually, viscerally and verbally to influence HIV policy and programme makers in Palembang.

From my research journey, I came to a deep understanding that being an Indonesian woman is full of complex challenges. The life of HIV-positive mothers is even more complicated, when their dreams to have a healthy child is clouded by social judgement and stigma and confusion in navigating the Indonesian health system. This research provides evidence that Indonesian women may not be aware of their HIV status. Often

---

[76] See https://www.youtube.com/watch?v=y4uebpiV2kQ

women only found their HIV status at a very late stage. Due to fears of stigmatization, women may choose to deny or hide their status and not accessing health services.

It is imperative to protect babies from HIV. But has not been easy for Indonesian women to access health services. Can we all, each of us, become the agent of change? Can we, as religious leaders, community leaders, health practitioners, policy makers, programme development, politicians, and neighbours and families protect our mothers, sisters, cousins, and nieces from HIV? Do we care to save 30 Indonesian babies and other 500 babies worldwide every day from HIV?

Reference list

Adimora, A. A., & Schoenbach, V. J. (2012). Social determinants of sexual networks, partnership formation, and sexually transmitted infections. In S. O. Aral, K. A. Fenton, & J. A. Lipshutz (Eds.), *The new public health and STD/HIV prevention: Personal, public and health systems approaches* (pp. 13-29). New York, NY: Springer Science & Business Media.

Agustina, R., Dartanto, T., Sitompul, R., Susiloretni, K. A., Achadi, E. L., Taher, A., . . . Shankar, A. H. (2019). Universal health coverage in Indonesia: Concept, progress, and challenges. *The Lancet, 393*, 75-102. https://doi.org/10.1016/S0140-6736(18)31647-7

Aldridge, J. (2015). *Participatory research: Working with vulnerable groups in research and practice*. Bristol, UK: Policy Press.

Amelya, M., Andriyana, H., Nababan, B., & Gunardi, E. R. (2016). *Postpartum contraceptive use among HIV positive women in Cipto Mangunkusumo Hospital Jakarta, Indonesia: A cross sectional study*. Paper presented at the 6th Congress of the Asia Pacific Initiative on Reproduction, Jakarta, Indonesia.

Amornwichet, P., Teeraratkul, A., Simonds, R., Naiwatanakul, T., Chantharojwong, N., Culnane, M., . . . Kanshana, S. (2002). Preventing mother-to-child HIV transmission: The first year of Thailand's national program. *Jama, 288*(2), 245-248. http://doi.org/10.1001/jama.288.2.245

Andajani, S., Chirawatkul, S., & Saito, E. (2015). Gender and water in Northeast Thailand: inequalities and women's realities. *Journal of International Women's Studies,* 16(2), 200-212. Retrieved from http://vc.bridgew.edu/jiws/vol16/iss2/13

Andajani, S., Hadiwirawan, O., & Sokang, Y. A. (2016). Women's leadership in Indonesia: Current discussion, barriers, and existing stigma. *Jurnal Perempuan (Indonesian Feminist Journal), 4*(1), 116-114. https://www.jurnalperempuan.org/

Andajani, S., Lubis, D., & Graham-Davies, S. (2015). Razia terhadap LGBT sebagai agenda moralitas palsu: Kajian pemberitaan media di Indonesia (Raid on LGBT as a fake morali agenda: A study of news media in Indonesia). *Jurnal Perempuan (Indonesian Feminist Journal), 20*(4), 97-107. https://www.jurnalperempuan.org/

Angkasawati, T. J., & Arifin, A. (2010). Pengetahuan komprehensif dan sikap terhadap HIV/Aids pada kelompok wanita usia subur (WUS) di Indonesia tahun 2007 (Comprehensive knowledge and attitude related to HIV among childbearing age women in Indonesia, 2007). *Bulletin of Health System Research, 13*(2), 140-150. http://ejournal.litbang.depkes.go.id/

Anindita, M., & Shaluhiyah, Z. (2016). Non disclosure of HIV positive status of women to their partners: Implication for PMTCT in Central Java Indonesia. *Jurnal Promosi Kesehatan Indonesia (Journal of Health Promotion Indonesia), 8*(1), 39-48. https://doi.org/10.14710/jpki.8.1.39-48

Anugerah, P. (2015, 1 December). Data Kemenkes Ibu rumah rangga rertinggi HIV (MoH data: Mothers and wives dominates new HIV cases). *BBC Indonesia*. Retrieved from https://www.bbc.com/indonesia

Arivia, G., & Boangmanalu, A. G. (2016). When the state is absent: A study of LGBT community in Jakarta. *Jurnal Perempuan (Indonesian Feminist Journal), 4*(1), 4-12. https://www.jurnalperempuan.org/

Astbury, J. (1996). *Crazy for you: The making of women's madness.* London, UK: Oxford University Press.

Avert. (2019). Prevention of Mother-to-Child Transmission (PMTCT) of HIV *Global information and education on HIV and AIDS.* Retrieved from https://www.avert.org/professionals/hiv-programming/prevention/prevention-mother-child

Ayubi, Z. M. (2015). *Gendered Morality: Classical Islamic ethics of the self, family, and society.* (Doctoral dissertation), University of North Caroline, Chapel Hill. Retrieved from https://cdr.lib.unc.edu/concern/dissertations/6t053g947

Ayubi, Z. M. (2019). *Gendered morality: Classical Islamic ethics of the self, family, and society*. New York, NY: Columbia University Press.

Badriah, F., Tahangnacca, M., Alkaff, R., Abe, T., & Hanifah, L. (2018). Implementation of Prevention of Mother to Child Transmission of HIV program in South Jakarta. *Kesmas: National Public Health Journal, 12*(4), 159-164. http://dx.doi.org/10.21109/kesmas.v12i4.1707

Baintung, B. (2016). Multi-tasking breastfeeding mamas: Morality and gender in health promotion. Retrieved from https://indonesiaatmelbourne.unimelb.edu.au/multi-tasking-breastfeeding-mamas-morality-and-gender-in-health-promotion/

Banks, J. A. (1998). The lives and values of researchers: Implications for educating citizens in a multicultural society, *Educational Researchers, 27*(7), 4-17. https://www.jstor.org/

Baral, S., Logie, C. H., Grosso, A., Wirtz, A. L., & Beyrer, C. (2013). Modified social ecological model: A tool to guide the assessment of the risks and risk contexts of HIV epidemics. *BMC public health, 13*(482), 1-8. https://doi.org/10.1186/1471-2458-13-482

Bennett, L. R. (2005). *Women, Islam and modernity: Single women, sexuality and reproductive health in contemporary Indonesia*. London, UK: Routledge.

Bennett, L. R. (2007). Zina and the enigma of sex education for Indonesian Muslim youth. *Sex Education, 7*(4), 371-386.

Bennett, L. R. (2015). Sexual morality and the silencing of sexual helath within Indonesian infertility care. In L. R. Bennett & S. G. Davies (Eds.), *Sex and sexualities in contemporary Indonesia: Sexual politics, health, diversity and representations* (pp. 148-166). London, UK: Routledge.

Bennett, L. R., & Davies, S. G. (Eds.). (2015). *Sex and sexualities in contemporary Indonesia: Sexual politics, health, diversity and representations*. London, UK: Routledge.

Bijker, R., Jiamsakul, A., Kityo, C., Kiertiburanakul, S., Siwale, M., Phanuphak, P., . . . Sim, B. L. (2017). Adherence to antiretroviral therapy for HIV in sub-Saharan Africa and Asia: A comparative analysis of two regional cohorts. *Journal of the International AIDS Society, 20*(1), 1-10. https://doi.org/10.7448/IAS.20.1.21218

Blackburn, S., Smith, B. J., & Syamsiyatun, S. (Eds.). (2008). *Indonesian Islam in a new era*. Clayton, Australia: Monash University Press.

Blackstone, S. R., Nwaozuru, U., & Iwelunmor, J. (2018). Antenatal HIV testing in Sub-Saharan Africa during the implementation of the millennium development goals: A systematic review using the PEN-3 cultural model. *International Quarterly of Community Health Education, 38*(2), 115-128. https://doi.org/10.1177/0272684X17749576

Body Positive Inc (Producer). (2016, April 25). Lets talk about HIV-Gay men's sexual health. Retrieved from https://www.youtube.com/watch?v=mOlYWlC5Ysk

Botha, C. S., & Hay, J. (2016). Narratives of adolescent girls journeying via feminist participatory action research through the aftermath of divorces. *Africa Education Review, 13*(2), 15. https://doi.org/10.1080/18146627.2016.1224105

Bottorff, L., Joan,, Oliffe, L., Joan,, Robinson, A., Carole, , & Carey, J. (2011). Gender relations and health research: A review of current practices. *International Journal for Equity in Health, 10*(60), 1-8. https://doi.org/10.1186/1475-9276-10-60

Bowleg, L. (2012). The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. *American Journal of Public Health, 102*(7), 1267-73. https://doi.org/10.2105/AJPH.2012.300750

Brawner, B. M. (2014). A multilevel understanding of HIV/AIDS disease burden among African American women. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 43*(5), 633-643. http://www.doi.org/10.1111/1552-6909.12481

Brydon-Miller, M., Maguire, P., & McIntyre, A. (Eds.). (2004). *Traveling companions: Feminism, teaching, and action research*. London, UK: Greenwood Publishing Group.

Bukhari, Muslim. (n.d). *Sahih Bukhari.* Retrived from https://www.sahih-bukhari.com/Pages/results.php

Burns, D., & Chantler, K. (2011). Feminist methodologies. In B. Somekh & C. Lewin (Eds.), *Theory and methods in social research* (pp. 70-76). Los Angeles, CA: Sage.

Busza, J., Walker, D., Hairston, A., Gable, A., Pitter, C., Lee, S., . . . Mpofu, D. (2012). Community-based approaches for prevention of mother to child transmission in resource-poor settings: A social ecological review. *Journal of the International AIDS Society, 15 (Suppl 2)*(17373), 1-11. http://doi.org/10.7448/ias.15.4.17373

Butt, L. (2011). Can you keep a secret? Pretences of confidentiality in HIV/AIDS counseling and treatment in Eastern Indonesia. *Medical Anthropology, 30*(3), 319-338. http://doi.org/10.1080/01459740.2011.560585.

Butt, L. (2015). Sexual tensions HIV-positive women in Papua. In L. R. Bennett & S. G. Davies (Eds.), *Sex and sexualities in contemporary Indonesia: Sexual politics, health, diversity and representations* (pp. 109-128). London,UK: Routledge Taylor & Francis Group.

Butt, L., Munro, J., & Numbery, G. (2017). Adding insult to injury: Experiences of mobile HIV-positive women who return home for treatment in Tanah Papua, Indonesia. In J. Tayler & H. Lee (Eds.), *Mobilities of Return: Pacific Perspectives* (pp. 147-170). Canberra, Australia: ANU Press.

Campbell, M. (2007). Mother/non-mother: Ibuism as subtext in the literary works of Ayu Utami. *RIMA: Review of Indonesian and Malaysian Affairs, 41*(2), 41-66. Retrieved from http://search.informit.com.au.ezproxy.aut.ac.nz/

Candraningrum, D. (2015). State, sexuality, and mother's narrative piracy (*Negara, seksualitas dan pembajakan narasi ibu*). Retrieved from https://www.jurnalperempuan.org/blog/negara-seksualitas-dan-pembajakan-narasi-ibu

Carpiano, R. M. (2009). Come take a walk with me: The "go-along" interview as a novel method for studying the implications of place for health and well-being. *Health & Place, 15*(1), 263-272. http://dx.doi.org/10.1016/j.healthplace.2008.05.003

Carr, E. S. (2003). Rethinking empowerment theory using a feminist lens: The importance of process. *Affilia, 18*(1), 8-20. http://doi.org/10.1177/0886109902239092

Chanthasukh, S. (2019). *Decision making and contraception: Perceptions and experiences of Thai-Isan adolescents* (Doctoral dissertation, Auckland University of Technology, Auckland, New Zealand)

Chirawatkul, S., Rungreongkulkij, S., Jongudomkarn, D., Sawangchareon, K., Anusornteerakul, S., Rujiraprasert, N., . . . Chareonwong, S. (2012). Working with young adolescents on the prevention of and dealing with Teenage Pregnancy. Unpublished manuscript: WHO Collaborating Centre for Research and Training on Gender and Women's Health, Khon Kaen University, Thailand.

Chersich, M., Newbatt, E., Ng'oma, K., & de Zoysa, I. (2018). UNICEF's contribution to the adoption and implementation of option B+ for preventing mother-to-child transmission of HIV: A policy analysis. *Globalization and Health, 14*(55), 1-13. http://www.doi.org/10.1186/s12992-018-0369-2

Chiya, H. W., Naidoo, J. R., & Ncama, B. P. (2018). Stakeholders' experiences in implementation of rapid changes to the South African prevention of mother-to-child transmission programme. *African Journal of Primary Health Care & Family Medicine, 10*(1(a17888)), 1-10. http://dx.doi.org/10.4102/phcfm.v10i1.1788

Conn, C., Nayar, S., Lubis, D., Maibvisira, C., & Modderman, K. (2017). Vulnerable youth as prosumers in HIV prevention: Studies using participatory action research. *JMIR Public Health and Surveillance, 3*(3), e53. https:///www.doi.org/10.2196/publichealth.7812

Connor, E. M., Sperling, R. S., Gelber, R., Kiselev, P., Scott, G., O'sullivan, M. J., . . . Jacobson, R. L. (1994). Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. *New England Journal of Medicine, 331*(18), 1173-1180. https://www.doi.org/10.1056/NEJM199411033311801

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process.* London, UK: SAGE.

Damar, A. P. (2014). *HIV, AIDS and gender issues in Indonesia: Implications for policy- An application of complexity theory.* (Doctoral dissertation, University of South Africa, South Africa). Retrieved from http://uir.unisa.ac.za/handle/10500/18691

Damar, A. P., & du Plessis, G. (2010). Coping versus grieving in a 'death-accepting'society: AIDS-bereaved women living with HIV in Indonesia. *Journal of Asian and African studies, 45*(4), 424-431. Retrieved from https://www.ncbi.nlm.nih.gov

George, D., Rovniak, L., & Kraschnewski, J. (2013). Dangers and opportunities for social media in medicine. *Clinical Obstetrician Gynecology, 56*(3), 4-6. http://doi.org/10.1097/GRF.0b013e318297dc38

Darak, S., Panditrao, M., Parchure, R., Kulkarni, V., Kulkarni, S., & Janssen, F. (2012). Systematic review of public health research on prevention of mother-to-child transmission of HIV in India with focus on provision and utilization of cascade of PMTCT services. *BMC Public Health, 12*(1), 320. http://doi.org/10.1186/1471-2458-12-320

Davies, S. G. (2015). Surveilling sexuality in Indonesia. In L. R. Bennett & S. G. Davies (Eds.), *Sex and sexualities in contemporary Indonesia: Sexual politics, health, diversity and representations* (pp. 29-51). London, UK: Routledge.

Davies, S. G. (2019). Islamic identity and sexuality in Indonesia. In S. Ratuva (Ed.), *The Palgrave handbook of ethnicity* (pp. 1-14). Singapore: Palgrave Macmillan.

Davies, S. G., & Najmah. (2020a). Im/moral healthcare: HIV and universal health coverage in Indonesia *Sexual and Reproductive Health Matters (In process)*.

Davies, S., G, & Najmah. (2020b). Covid and HIV/AIDS in Indonesia. Retrieved from https://soundcloud.com/sseac-stories/covid19-and-hiv-aids-in-indonesia.

De Cock, K. M., Fowler, M. G., Mercier, E., de Vincenzi, I., Saba, J., Hoff, E., . . . Shaffer, N. (2000). Prevention of mother-to-child HIV transmission in resource-poor countries: Translating research into policy and practice. *Jama, 283*(9), 1175-1182. http://doi.org/10.1001/jama.283.9.1175

Demartoto, A., Zunariyah, S., & Bellarminus Soemanto, R. (2016). The accessibility of HIV-infected poor women to the Prevention of Mother to Child Transmission Service in Surakarta Indonesia. *Indian Journal of Community Health, 28*(4), 317-323. http://www.iapsmupuk.org/journal/index.php/IJCH

Denzin, N. K., & Lincoln, Y., S. (Eds.). (2008). *Strategies of qualitative inquiry* (Vol. 3). Los Angeles, CA: Sage.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2005). *The SAGE handbook of qualitative research* (3th ed.). Thousand Oaks, CA: Sage.

Department of Health and Human Services. (2019). Supportive environments. Retrieved from https://www.dhhs.tas.gov.au/wihpw/principles/supportive_environments

Dewi, K. H. (2015). *Indonesian women and local politics: Islam, gender and networks in post-Suharto Indonesia* (Vol. 14). Singapore, Singapore: NUS Press.

Dewi, K. H. (2017). Piety and sexuality in a public sphere: Experiences of Javanese muslim women's political leadership. *Asian Journal of Women's Studies, 23*(3), 340-362. https://doi.org/10.1080/12259276.2017.1352250

Djajadiningrat-Nieuwenhuis, M. (1987). Ibuism and priyayization: Path to power? In E. Locher-Scholten & A. Niehof (Eds.), *Indonesian Women in Focus: Past and Present Notions* (pp. 127-143). Leiden, Netherlands: KITLV Press.

Doucet, A. M., Natasha S. (2007). Feminist methodologies and epistemology In C. D. Bryant & D. L. Peck (Eds.), *21th century sociology: A reference handbook* (pp. 36-42). Thousand Oaks, CA: Sage publications.

Drake, A. L., Wagner, A., Richardson, B., & John-Stewart, G. (2014). Incident HIV during pregnancy and postpartum and risk of mother-to-child HIV transmission: A systematic review and meta-analysis. *PLoS Medicine, 11*(2:e1001608), 1-16. https://journals.plos.org/plosmedicine/

Ebrahim, A. F. M. (2007). *Islam and HIV/AIDS*. Paper presented at the Convention on HIV/AIDS (HIV/AIDS: Scientific, ethical and Islamic dimensions), Istambul, Turkey.

Encyclopaedia Britannica. (2018). Srivijaya Empire, historical kingdom, Indonesia. Retrieved from https://www.britannica.com/place/Srivijaya-empire

Evans, D. B., Hsu, J., & Boerma, T. (2013). *Universal health coverage and universal access*. Retrieved from https://www.who.int/gender-equity-rights/understanding/accessibility-definition/en/

Fahlevi, D. (2015). Impact of implementation of the great events on development in South Sumatra province (*Dampak pelaksanaan even besar terhadap pembangunan di provinsi Sumatera Selatan*). Retrieved from http://sumsel.bps.go.id/webbaru/site/content/241

Firmansyah, R. (2015, December 1). Wives and mothers are vulnerable to contract to HIV compared to sex workers (*Ibu Rumah Tangga di DIY Rentan Terkena HIV/AIDS Ketimbang PSK*). *Tribun Jogya*. Retrieved from http://jogja.tribunnews.com/

Frankopan, P. (2018). *The Silk Roads: A new history of the world.* London, UK: Bloomsbury Publishing.

Formen, A., & Nuttall, J. (2014). Tensions between discourses of development, religion, and human capital in early childhood education policy texts: The case of Indonesia. *International Journal of Early Childhood, 46*(1), 15-31. https://doi.org/10.1007/s13158-013-0097-y

Fraser, K. D., & al Sayah, F. (2011). Arts-based methods in health research: A systematic review of the literature. *Arts & Health, 3*(2), 110-145. http://www.doi.org/10.1080/17533015.2011.561357

French, M. (1985). *Beyond power: On men, women, and morals*. New York, NY: Summit Books.

Gatenby, B., & Humphries, M. (2000). Feminist participatory action research: Methodological and ethical issues. *Women's Studies International Forum, 23*(1), 89-105. https://doi.org/10.1016/S0277-5395(99)00095-3

Gaventa, J., & Cornwall, A. (2008). Power and knowledge. In P. Reason & H. Bradbury (Eds.), *Sage handbook of action research: Participative inquiry and practice* (Vol. 2, pp. 173-189). London, UK: SAGE.

Geertz, C. (1976). *The religion of Java*. Chicago, IL: University of Chicago Press.

Ghaliya, G. (2019, October 1). Indonesia gets first female speaker for House of Representatives. *The Jakarta Post*. Retrieved from https://www.thejakartapost.com/news/2019/10/01/indonesia-gets-first-female-speaker-for-house-of-representatives.html

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

Governor of Aceh. (2014). *Shariah Law (Hukum Jinayat) number 6 year of 2016*. Aceh, Indonesia: Governor of Aceh

Government of Indonesia (1945). The Constitution of the Republic Indonesia 1945 (*Undang-Undang Dasar 1945*). Retrieved from http://www.unesco.org/education/edurights/media/docs/b1ba8608010ce0c48966911957392ea8cda405d8.pdf

Government of Indonesia. (1974). *Law of marriage (Undang-Undang Perkawinan)*. Jakarta, Indonesia: GoI. Retrieved from http://www.kemenag.go.id/file/dokumen/UUPerkawinan.pdf.

Government of Indonesia. (1990). A change of Government Regulation number 10 in 1983 about Marriage and Divorce Permission for Public Servants (*Peraturan Pemerintah nomor 45 tentang perubahan peraturan 10 tahun 1983 tentang Izin Perkawinan dan Perceraian bagi Pegawai Negeri Sipil*). Retrieved from http://sdm.ugm.ac.id/web/sk/1990_PP-45-TH-1990_PERUBAHAN-PP-10-1983-IZIN-PERKAWINAN-DAN-PERCERAIAN-BAGI-PNS.pdf

Government of Indonesia. (2006). *Regulation of President of Indonesia: AIDS National Commission (Komisi Penanggulangan AIDS Nasional)*. Jakarta: Government of Indonesia Retrieved from https://www.kebijakanaidsindonesia.net/id/dokumen-kebijakan/send/17-peraturan-pusat-national-regulation/497-perpres-ri-no-75-tahun-2006-tentang-komisi-penanggulangan-aids.

Government of Indonesia. (2014). *Government of Indonesia regulation number 156 in 2014 about performance allowance of civil servants in department of finance (Peraturan pemerintah Republik Indonesia no 156 tahun 2014 tentang tunjangan kinerja pegawai di lingkungan kementrian keuangan)*. Jakarta, Indonesia: GoI. Retrieved from http://keuangan.unej.ac.id/wp-content/uploads/2015/06/PP-30-2015-Kenaikan-Gaji-PNS-2015-.pdf.

Government of Indonesia. (2015). *Government of Indonesia regulation number 30 in 2015 about.. (Peraturan pemerintah Republik Indonesia no 30 tahun 2015 tentang)*. Jakarta, Indonesia: GoI. Retrieved from http://keuangan.unej.ac.id/wp-content/uploads/2015/06/PP-30-2015-Kenaikan-Gaji-PNS-2015-.pdf.

Government of Indonesia. (n.d.). *Government regulation about abolishing sexual assault (Rancangan Undang-Undang penghapusan kekerasan seksual)*. Retrieved from http://www.dpr.go.id/doksileg/proses2/RJ2-20170201-043128-3029.pdf.

Gourlay, A., Birdthistle, I., Mburu, G., Iorpenda, K., & Wringe, A. (2013). Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: A systematic review. *Journal of the International AIDS Society*, *16*(18588), 1-21. https://doi.org/10.7448/IAS.16.1.18588

Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., & Hudson, M. (2002). What does' access to health care'mean? *Journal of Health Services Research & Policy, 7*(3), 186-188. https://doi.org/10.1258/135581902760082517

Gutierrez, L. M. (1990). Working with women of color: An empowerment perspective. *Social Work, 35*(2), 149-153. https://www.doi.org/10.1093/sw/35.2.149

Gutierrez, L. M. (1995). Understanding the empowerment process: Does consciousness make a difference? *Social Work Research, 19*(4), 229-237. https://www.jstor.org/

Hairston, A. F., Bobrow, E. A., & Pitter, C. S. (2012). Towards the elimination of pediatric HIV: Enhancing maternal, sexual, and reproductive health services. *International Journal of MCH and AIDS, 1*(1), 6-16. https://www.ncbi.nlm.nih.gov/pmc/

Hampanda, K. (2012). Vertical transmission of HIV in Sub-Saharan Africa: Applying theoretical frameworks to understand social barriers to PMTCT. *ISRN Infectious Diseases, 2013 (Article ID 420361)*, 1-5. http://dx.doi.org/10.5402/2013/420361

Handayani, T., & Sugiarti. (2002). *Konsep dan Teknik Penelitian Gender (Concept and Gender Research Method)*. Malang, Indonesia: Universitas Muhammadiyah Malang.

Harapan, H., Khalilullah, S. A., Anwar, S., Zia, M., Novianty, F., Putra, R. P., . . . Pratama, R. (2013). Discriminatory attitudes toward people living with HIV among health care workers in Aceh, Indonesia: A vista from a very low HIV caseload region. *Clinical Epidemiology and Global Health, 3*(1), 29-36. https://doi.org/10.1016/j.cegh.2013.08.001

Harding, S. G. (1987). Conclusion: Epistemiology questions. In S. G. Harding (Ed.), *Feminism and methodology: Social science issues*. (181-190). Bloomington, Indiana: Indiana University Press.

Hardon, A. P., Oosterhoff, P., Imelda, J. D., Anh, N. T., & Hidayana, I. (2009). Preventing mother-to-child transmission of HIV in Vietnam and Indonesia: diverging care dynamics. *Social Science & Medicine, 69*(6), 838-845. https://doi.org/10.1016/j.socscimed.2009.05.043.

Hasnain, M. (2005). Cultural approach to HIV/AIDS harm reduction in Muslim countries. *Harm Reduction Journal, 2*(23), 1-9. http://doi.org/10.1186/1477-7517-2-23

Hennink, M. M. (2007). *International focus group research: A handbook for the health and social sciences.* Cambridge, UK: Cambridge University Press.

Hesse-Biber, S. N. (2012). Feminist research, exploring, interrogating and transforming the interconnections of epistemology, methodology and method. In S. N. Hesse-Biber (Ed.), *The handbook of Feminist Research*. London, UK: SAGE.

Hesse-Biber, S. N., & Leavy, P. (2010). *The practice of qualitative research*. London, UK: Sage.

Heryanto, A. (2014). *Identity and pleasure: The politics of Indonesian screen culture*. Singapore, Singapore: NUS Press.

Hidayana, I. M., & Tenni, B. (2015). Negotiating risk -Indonesian couple navigating marital relationships, reproduction, and HIV. In L. R. Bennett & S. G. Davies

(Eds.), *Sex and sexualities in contemporary Indonesia: Sexual politics, health, diversity and representations*. London, UK: Routledge Taylor & Francis Group.

Higgins, J. A., Hoffman, S., & Dworkin, S. L. (2010). Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS. *American Journal of Public Health, 100*(3), 435-445.

Hirsch, J. S., Wardlow, H., Smith, D. J., Parikh, S., Phinney, H. M., & Nathanson, C. A. (2009). *The secret: Love, marriage, and HIV*: Vanderbilt university Press.

Hlartaithe, M., O, Grede, N., de Pee, S., & Bloem, M. (2014). Economic and social factors are some of the most common barriers preventing women from accessing maternal and newborn child health (MNCH) and prevention of mother-to-child transmission (PMTCT) services: A literature review. *AIDS and Behavior, 18*(5), 516-530. https://doi.org/10.1007/s10461-014-0756-5

Holden, S. (2003). *AIDS on the agenda: Adapting development and humanitarian programmes to meet the challenge of HIV/AIDS*. London, UK: An Oxfam publication in association with ActionAid and Save the Children, UK.

Hollen, C. V. (2007). Navigating HIV, pregnancy, and childbearing in South India: Pragmatics and constraints in women's decision making. *Medical Anthropology, 26*(1), 7-52. http://dx.doi.org/10.1080/01459740601021186

Ibrahim, K., & Songwathana, P. (2010). Cultural Care for People Living with HIV/AIDS in Muslim Communities in Asia: A literature review. *Thai Journal of Nursing Research-วารสาร วิจัย ทางการ พยาบาล, 13*(2), 148-157. https://www.tci-thaijo.org/index.php/PRIJNR/article/view/6445

Idele, P., Hayashi, C., Porth, T., Mamahit, A., & Mahy, M. (2017). Prevention of mother-to-child transmission of HIV and paediatric HIV care and treatment monitoring: From measuring process to impact and elimination of mother-to-child transmission of HIV. *AIDS and Behavior, 21*(1), 23-33. http://doi.org/10.1007/s10461-016-1670-9

Idrus, N., & Bennett, L. R. (2003). Presumed consent and marital violence in Bugis society. In L. M. L. Bennett (Ed.), *Violence against women in Asian societies* (pp. 41-60). London, UK: Routledge.

Ignatius, H. (2010). Why is SIHA policy important in controllong HIV and AIDS ? (*Kenapa Kebijakan SIHA penting dalam Penanggulangan HIV dan AIDS?*). Retrieved from http://www.kebijakanaidsindonesia.net/id/artikel/artikel-tematik/445-kenapa-kebijakan-siha-penting-dalam-penanggulangan-hiv-dan-aids

Imelda, J. D. (2011). *Mobilizing motherhood: Case study of two women's organizations advocating HIV prevention programs in Indonesia*. (Doctoral dissertation, Faculty of Social and Behavioural Sciences (FMG), Amsterdam). Retrieved from http://hdl.handle.net/11245/1.363831

Imelda, J. D. (2014). Disease interpretations and response among HIV-positive mothers. *Antropologi Indonesia (Indonesian Anthrophology), 35*(1), 4-16. https://doi/org/10.7454/ai.v35i1.4718

INAC. (2018). *National strategy and plan 2015-2019*. Retrieved from http://siha.depkes.go.id/portal/files_upload/SRAN_2015_2019_FINAL.pdf

Index Mundi. (2018). Maternal mortality rate in Asia. Retrieved from https://www.indexmundi.com/map/?v=2223&r=as&l=en

Indonesian Ministry of Religious Affairs. (1991). *Islamic Law Compilation*. Jakarta, Indonesia: Indonesian President.

Indonesian Parliament and President of Indonesian Republic. (2009). *Law number 35 year of 2009 about Narcotics (Undang Undang Republik Indonesia nomor 35 thaun 2009 tentang Narkotika)*. Jakarta, Indonesia: President of Indonesian Republic

infoKUA. (2019). Marriage regulations in Religious Offices 2019 and the fees for the registration (*Persyaratan nikah di KUA 2019 berikut dengan biayanya*). Retrieved from https://infokua.com/persyaratan-nikah-di-kua/

IPPI (2017a). *Arumi adventure (Pertualangan Arumi)*. Jakarta, Indonesia: IPPI, Global Fund & MoH.

IPPI (2017b). Evaluation of enhancement to sexual and reproductive health rights in 3 cities *(Evaluasi dampak peningkatan kapasitas HKSR di 3 kota)*. Jakarta, Indonesia: IPPI, UNAIDS, Indonesian-Ministry of Health.

Irvine, F., Roberts, G., & Bradbury-Jones. (2008). Translation. In P. Liamputtong (Ed.), *Doing cross-cultural research: Ethical and methodological perspectives (Vol. 34)*: Springer Science & Business Media.

Isgandarova, N. (2016). The Impact of maternity beliefs on reproductive health in Muslim societies. In M. A. a. D. M. O. Pappano (Ed.), *Muslim mothering*. Canada, Canada: Demeter.

Ishikawa, N., Ishigaki, K., Ghidinelli, M. N., Ikeda, K., Honda, M., Miyamoto, H., . . . Oka, S. (2011). Paediatric HIV and elimination of mother-to-child transmission of HIV in the ASEAN region: A call to action. *AIDS care, 23*(4), 413-416. http://www.doi.org/10.1080/09540121.2010.516338

Ismail, R., Voss, J. G., Woods, N. F., John-Stewart, G., Lowe, C., Nurachmah, E., . . . Boutain, D. (2018). A content analysis study: Concerns of Indonesian women infected with HIV by husbands who used intravenous drugs. *Journal of the Association of Nurses in AIDS Care, 29*(6), 914-923.

Jacubowski, N. (2008). Marriage is not a safe place: Heterosexual marriage and HIV-related vulnerability in Indonesia. *Culture, Health & Sexuality, 10*(1), 87-97. http://doi.org/10.1080/13691050601058573

Jategaonkar, N., & Ponic, P. (2011). Unsafe & unacceptable Housing: Health & policy implications for women leaving violent relationships. *Women's Health and Urban Life, 10*(1), 32-58. http://hdl.handle.net/1807/27218

Kanengoni, B., Andajani-Sutjahjo, S., & Holroyd, E. (2019). Women's experiences of disrespectful and abusive maternal health care in a low resource rural setting in Eastern Zimbabwe. *Midwifery, 76*. https://doi.org/10.1016/j.midw.2019.06.003

Kasenga, F., Byass, P., Emmelin, M., & Hurtig, A.-K. (2009). The implications of policy changes on the uptake of a PMTCT programme in rural Malawi: First three years of experience. *Global Health Action, 2*(1), 1-7. http://www.doi.org/10.3402/gha.v2i0.1883

Killen, M., & Smetana, J. G. (2013). *Handbook of moral development*. New York, NY: Psychology Press.

KitaSetara. (2017). HIV/AIDS mitigation in Indonesia in the future, where should we go? Retrieved from https://kumparan.com/kita-setara/mau-dibawa-ke-mana-penanggulangan-aids-di-indonesia-di-masa-mendatang

Kramarae, C., & Spender, D. (Eds.). (1992). *The knowledge explosion: Generation of feminist scholarship*. New York, NY: NY. Teacher's college press.

Kuhn, T., S,. (2012). *The structure of scientific revolutions* (Vol. 4). Chicago, Illinois: The University of Chicago.

Kuntowijoyo. (2001). *Muslims without mosques: Religious, cultural and political essays in the frame of transcendental structuralism (Muslim tanpa masjid: Esai-esai agama, budaya, dan politik dalam bingkai strukturalisme transendental)*. Jakarta: Mizan.

Lagomarsino, G., Garabrant, A., Adyas, A., Muga, R., & Otoo, N. (2012). Moving towards universal health coverage: Health insurance reforms in nine developing countries in Africa and Asia. *The Lancet, 380*(9845), 933-943. https://doi.org/10.1016/S0140-6736(12)61147-7

Lawson, H. A., Caringi, J., Pyles, L., Bozlak, C., & Jurkowski, J. (2015). *Participatory action research-pocket guides to social work research methods*. Oxford, UK: Oxford University Press.

Lazuardi, E., Bell, S., & Newman, C. E. (2018). A 'scoping review'of qualitative literature about engagement with HIV care in Indonesia. *Sexual Health, 15*(4), 283-291. https://doi.org/10.1071/SH17163

Leavy, P. (2015). *Method meets art: Arts-based research practice*. New York, NY: Guilford Publications.

Liamputtong, P. (2011). *Focus group methodology: Principle and practice*. Los Angeles, CA: Sage Publications.

Liamputtong, P., & Ezzy, D. (2005). *Qualitative research methods*. Melbourne, Australia: Oxford.

Liamputtong, P., & Haritavorn, N. (2014). My life as mae tid chua [mothers who contracted HIV disease]: Motherhood and women living with HIV/AIDS in central Thailand. *Midwifery, 30*(12), 1166-1172. http://www.doi.org/10.1016/j.midw.2014.04.003

Liamputtong, P., & Haritavorn, N. (2014). To tell or not to tell: Disclosure to children and family amongst Thai women living with HIV/AIDS. *Health Promotion International, 31*(1), 23-32. https://www/doi.org/10.1093/heapro/dau057.

Liem, A., & Adiyanti, M. G. (2013). "Bidan cantik": Psychoeducation on HIV and AIDS to improve the service quality of midwives at Yogyakarta public health center. *HIV & AIDS Review, 12*(1), 14-22. https://doi.org/10.1016/j.hivar.2013.02.001

Lin, K., McElmurry, B. J., & Christiansen, C. (2007). Women and HIV/AIDS in China: Gender and vulnerability. *Health Care for Women International, 28*(8), 680-699. https://doi.org/10.1080/07399330701465010

Lindegren, M. L., Byers Jr, R. H., Thomas, P., Davis, S. F., Caldwell, B., Rogers, M., . . . Fleming, P. L. (1999). Trends in perinatal transmission of HIV/AIDS in the

United States. *Jama, 282*(6), 531-538. https://www.doi.org/10.1001/jama.282.6.531

Lindquist, J. (2004). Veils and ecstasy: Negotiating shame in the Indonesian borderlands. *Ethnos, 69*(4), 487-508. https://doi.org/10.1080/0014184042000302317

Locher-Scholten, E., & Niehof, A. (Eds.). (1987). *Indonesian women in focus: Past and present notions*. Leiden, Netherlands: KITLV Press.

Lodi, S., Phillips, A., Touloumi, G., Geskus, R., Meyer, L., Thiébaut, R., . . . Babiker, A. (2011). Time from human immunodeficiency virus seroconversion to reaching CD4+ cell count thresholds< 200,< 350, and< 500 cells/mm3: Assessment of need following changes in treatment guidelines. *Clinical Infectious Diseases, 53*(8), 817-825. http://www.doi.org/10.1093/cid/cir494.

Lubis, D. S. (2018). *Creating space for young men who have sex with men (YMSM) to develop ideas on using the internet for HIV prevention.* (Doctoral dissertation, Auckland University of Technology, Auckland, New Zealand). Retrieved from https://openrepository.aut.ac.nz/handle/10292/11684

Lubis, D. S., Wulandari, L., Suariyani, N. L. P., Adhi, K. T., & Andajani, S. (2019). Private midwives' perceptions on barriers and enabling factors to Voluntary Counselling and HIV Test (VCT) in Bali, Indonesia. *National Public Health Journal (Kesmas), 14*(1). http://dx.doi.org/10.21109/kesmas.v14i1.2708

Lumbantoruan, C., Kermode, M., Giyai, A., Ang, A., & Kelaher, M. (2018). Understanding women's uptake and adherence in option B+ for prevention of mother-to-child HIV transmission in Papua, Indonesia: A qualitative study. *PloS One, 13*(6:e0198329), 1-17. https://doi.org/10.1371/journal

Lykes, M. B., & Coquillon, E. (2007). Participatory and action research and feminisms: Towards transformative praxis In S. N. Hesse-Biber (Ed.), *Handbook of feminist research: Theory and praxis* (pp. 297-326). Thousand Oaks, CA: SAGE Publications.

Lykes, M. B., & Crosby, A. (2014). Feminist practice of action and community research. In S. N. Hesse-Biber (Ed.), *Feminist research practice: A primer* (pp. 145-181). Thousand Oaks, CA: SAGE publications.

Lykes, M. B., & HershBerg, R. M. (2012). Participatory action research and feminism: Social inequalities and transformative praxis. In S. N. Hesse-Biber (Ed.), *Handbook of feminist research: Theory and praxis*. Thousand Oaks, CA: SAGE Publications.

Lykes, M. B., Mateo, A. C., Anay, J. C., Caba, A. L., Ruiz, U., & Williams, J. W. (1999). Telling stories—rethreading lives: Community education, women's development and social change among the Maya Ixil. *International Journal of Leadership in Education, 2*(3), 207-227. https://doi.org/10.1080/136031299293039

Lykke, N. (2010). *Feminist studies, a guide to intersectional theory, methodology and writing*. New York, NY: Routledge.

Madhivanan, P., Krupp, K., Kulkarni, V., Kulkarni, S., Vaidya, N., Shaheen, R., . . . Fisher, C. (2014). HIV testing among pregnant women living with HIV in India: are private healthcare providers routinely violating women's human rights? *BMC International Health and Human Rights, 14*(1), 1-9. https://doi.org/10.1186/1472-698X-14-7

Maguire, P. (1987). *Doing participatory research: A feminist approach.* Amherst, Massachusetts: University of Massachusetts.

Maguire, P. (1996). Considering more feminist participatory research: What's congruency got to do with it? *Qualitative Inquiry, 2*(1), 106-118. https://doi.org/10.1177/107780049600200115

Maguire, P. (2006). Uneven ground: Feminisms and action research. In P. R. a. H. Bradbury (Ed.), *Handbook of action research* (pp. 60-80). London, UK: SAGE.

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres, G., & Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS 22*(Suppl 2), 1-20. https://www.doi.org/10.1097/01.aids.0000327438.13291.62

Maharani, D. (2017, December 1). Why did more wives and mothers get HIV transmission? (*Mengapa banyak ibu rumah tangga terinfeksi HIV?*). *KOMPAS.* Retrieved from https://lifestyle.kompas.com.

Mahendra, G. K. (2018). Critics on disbanding roles of National AIDS Commission. Retrieved from https://geotimes.co.id/opini/kritik-penghentian-tugas-komisi-penanggulangan-aids/

Mahendradhata, Y., Trisnantoro, L., Listyadewi, S., Soewondo, P., Marthias, T., Harimurti, P., & Prawira, J. (2017). *The Republic of Indonesia health system review*. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/254716/9789290225164-eng.pdf?sequence=1&isAllowed=y

Maibvisira, C. (2018). *"Sex...is a good thing": Creating a space for the voices of young Zimbabweans to shape school-based HIV prevention-orientated sexuality education.* (Doctoral dissertation, Auckland University of Technology, Auckland, New Zealand). Retrieved from https://openrepository.aut.ac.nz/handle/10292/12549

Marbun, J. (2013). The controversy of condom campaign. *5 December 2013.* Retrieved from https://www.republika.co.id/berita/en/national-politics/13/12/05/mxb1qn-the-controversy-of-condom-campaign

Marsden, W. (1788). *The history of Sumatra*. London, UK: J. M'CREERY, BLACK-HORSE-COURT. Retrieved from http://www.gutenberg.org/files/16768/16768-h/16768-h.htm - ch-15.

Marshall, C., & Rossman, G. B. (2016). *Designing qualitative research*. Los Angeles, CA: Sage publications.

Martin-Anatias, N. (2018a). In Indonesia, a sexist term for ‘the other woman. Retrieved from https://theconversation.com/in-indonesia-a-sexist-term-for-the-other-woman-92290

Martin-Anatias, N. (2018b). On Being a “Good” Indonesian Muslim Woman: An Autoethnography. *Humanity & Society*, 43 (4), 351-374. https://doi.org/10.1177/0160597618814872

Mclntyre, A. (2008). *Participatory action research*. Thousand Oaks, UK: SAGE.

McNally, S., & Grierson, J. (2015). Belonging, community and identity : Gay men in Indonesia. In L. R. Bennett & S. G. Davies (Eds.), *Sex and sexualities in contemporary Indonesia: Sexual politics, health, diversity and representations*. London, UK: Routledge.

Merriam, S. B., Johnson-Bailey, J., L., M. Y., , Kee, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education*, *20*(5), 405-416. http://www.doi.org/10.1080/02601370120490

Merriam-webster. (2019a). Vulnerability. Retrieved from https://www.merriam-webster.com/thesaurus/vulnerability

Merriam-webster. (2019b). Resourceful. Retrieved from https://www.merriam-webster.com/dictionary/resourceful#other-words

Merriam-webster. (2020). Deception. Retrieved from https://www.merriam-webster.com/dictionary/deception

Merton, R. K. (1972). Insiders and outsiders: A chapter in the sociology of knowledge. *American Journal of Sociology, 78*(1), 9-47. https://www.jstor.org/

Meyer, D. T. (2002). *Gender in the mirror: Cultural imagery and women's agency*. London, UK: Oxford University Press on Demand.

Mills, M. B. (2017). Gendered morality tales: Discourses of gender, labour, and value in globalising Asia. *The Journal of Development Studies*, *53*(3), 14. https://doi.org/10.1080/00220388.2016.1184251

Ministry of Education and Culture. (2018). *Jumlah data satuan pendidikan sekolah per kabupaten/kota di Palembang (Number of schools in cities and regencies in Palembang)*. Jakarta, Indonesia: Ministry of Education and Culture Retrieved from http://referensi.data.kemdikbud.go.id/index11.php?kode=116000&level=2, .

Mitchell, C. M., & Sommer, M. (2016). Participatory visual methodologies in global public health. *Global public health*, *11*(5-6), 521-527. https://www.doi.org/10.1080/17441692.2016.1170184

MoH. (2010). *National Report-Basic Health Survey (RISKESDAS) 2010*. Retrieved from http://kesga.kemkes.go.id/images/pedoman/Riskesdas%202010%20Nasional.pdf

MoH. (2012a). *National guidelines of Prevention of Mother to Children of HIV Transmission (PMTCT) program* Jakarta, Indonesia: MoH & Ministry of Law and Human Rights.

MoH. (2012b). Transmission mode of HIV vulnerabile population, ibu rumah tangga and children in getting HIV in Indonesia (T. D. o. M. Health, Trans.). In T. p. o. M. t. C. T. o. H. P. Program (Ed.), *Sakti, Gita Maya, Orientasi Pencegahan Penularan HIV dari Ibu ke Anak (PPIA) Jakarta, 24-27 November 2015*. Jakarta, Indonesia: The Directorate of Maternal Health, Ministry of Health, Indonesia.

MoH. (2013a). *MoH regulation about guidelines for the Prevention of HIV transmission from mother to child Number 51 in 2013 (Permenkes no 51 tahun 2013 tentang Pedoman Pencegahan Penularan HIV dari ibu ke anak or PPIA)*. Jakarta, Indonesia: MoH.

MoH. (2013b). *MoH regulation of controlling HIV and AIDS number 21 in 2013 (Permenkes no 21 tahun 2013 tentang Penanggulangan HIV dan AIDS)*. Jakarta, Indonesia: MoH & Ministry of Law and Human Rights. Retrieved from https://www.kemhan.go.id/itjen/wp-content/uploads/2017/03/bn654-2013.pdf.

MoH. (2013c). *National action plan of Prevention of Mother to Child Transmission (PMTCT) program, Indonesia 2013-2017.* Jakarta, Indonesia: MoH.

MoH. (2013d). *National guidelines of Prevention Mother to Child Transmission of HIV.* Jakarta, Indonesia: MoH Retrieved from http://pppl.depkes.go.id/_asset/_regulasi/94_PMK No. 51 ttg Pencegahan Penularan HIV Ibu ke Anak.pdf.

MoH. (2013e). *National report-basic health survey (RISKESDAS) 2013*. Retrieved from Jakarta, Indonesia: http://www.depkes.go.id/resources/download/general/Hasil Riskesdas 2013.pdf

MoH. (2014a). *Integrated Biological and Behavioral Survey (IBBS) 2013*. Jakarta, Indonesia: MoH.

MoH. (2014b). *MoH regulation number 87 in 2014 about Antiretroviral treatment (Permenkes no 87 tahun 2014).* Jakarta, Indonesia: MoH & Ministry of Law and Human Rights. Retrieved from http://siha.depkes.go.id/portal/files_upload/Buku_Permenkes_ARV_Cetak.pdf.

MoH. (2014c). *MoH regulation number 97 in 2014 about health service during pregnancy planning, pregnancy, delivery babies and implementation of family planning, sexual health, and maternal health services (Permenkes no. 97 tahun 2014 tentang pelayanan kesehatan masa sebelum hamil, masa hamil, persalinan, dan masa sesudah melahirkan, penyelengaraan pelayananan kontrasepsi, serta pelaynan kesehatan seksual)).* Jakarta, Indonesia: MoH & Ministry of Law and Human Rights. Retrieved from http://kesga.kemkes.go.id/images/pedoman/PMK No. 97 ttg Pelayanan Kesehatan Kehamilan.pdf.

MoH. (2014d). *MoH regulation of the application of counselling and HIV test number 74 in 2014 (Permenkes no.74 tahun 2014 tentang pedoman pelaksanaan konseling dan tes HIV).* Jakarta, Indonesia: MoH & Ministry of Law and Human Rights. Retrieved from https://aidsfree.usaid.gov/sites/default/files/hts_policy_indonesia_2014.pdf.

MoH. (2015a). *MoH regulation of implementation of laboratory test for women who are pregnant, labour and after delivery in health settings and other referral services no 25 in 2015 (Permenkes no. 25 tahun 2015 tentang Penyelenggaraan pemeriksaan laboratorium untuk ibu hamil, bersalin, dan nifas di fasilitas pelayanan kesehatan dan jaringan pelayananya).* Jakarta, Indonesia: MoH & Ministry of Law and Human Rights. Retrieved from https://www.persi.or.id/images/regulasi/permenkes/pmk252015.pdf.

MoH. (2015b). *National management guidelines of prevention of HIV and Syphilis from mothers to children (Pedoman manajemen program Pencegahan Penularan HIV dan Sifilis dari ibu ke anak).* Jakarta, Indonesia: Directorate of Maternal and Children Health.

MoH. (2015c). *Pocket book for financing of national health insurance programme for HIV-AIDS and STIs in healthcare providers (Buku saku pembiayaan Jaminan Kesehatan Nasional (JKN) layanan HIV-AIDS IMS di fasilitas kesehatan).*

Jakarta, Indonesia: MoH Retrieved from http://www.siha.depkes.go.id/portal/files_upload/1_h__Draft_JKN_HIV_211215_Final.pdf.

MoH. (2016). *MoH regulation of basic standard services in health number 43 in 2016 (Permenkes no. 43 tahun 2016 tentang standar pelayanan minimal bidang kesehatan)*. Jakarta, Indonesia: MoH & Ministry of Law and Human Rights. Retrieved from https://djsn.go.id/storage/app/uploads/public/58d/486/f01/58d486f010a3f067108647.pdf.

MoH. (2017). *Size Estimation of HIV Key Population in Indonesia 2016* Retrieved from https://drive.google.com/file/d/1CBS2t_bL2m2Pg9EI3w6KjHXUScdndK89/view

MoH. (2017a). *MoH regulation of elimination of HIV, Syphilis and Hepatitis B from mother to children number 52 in 2017 (Permenkes no.52 tahun 2017)*. Jakarta, Indonesia: MoH & Ministry of Law and Human Rights. Retrieved from https://www.persi.or.id/images/regulasi/permenkes/pmk522017.pdf.

MoH. (2017b). *Report of situation analysis of HIVAIDS in 2017*, Jakarta, Indonesia: MoH. Retrieved from http://www.aidsindonesia.or.id/list/7/Laporan-Menkes.

MoH. (2018). *Report of situation analysis of HIVAIDS in 2018*, Jakarta, Indonesia: MoH. Retrieved from http://www.aidsindonesia.or.id/list/7/Laporan-Menkes.

MoH, & UGM. (2015). *Report of the operational research: Treatment procedures in continuum care of HIV program in Yogyakarta and Semarang (Prosedur pengobatan pada layanan komprehensif HIV-AIDS berkesinambungan-LKB- di Kota Yogyakarta dan Kota Semarang)*. Yogyakarta, Indonesia: MoH & Centre of Health Policy and Management-UGM.

MoH, & UNFPA. (2012). *Disparity of access and quality: Review of maternal mortality in five regions in Indonesia* Retrieved from https://indonesia.unfpa.org/sites/default/files/pub-pdf/Disparity_of_Access_Quality_Review_of_Maternal_Mortality_in_5_Regions_in_Indonesia.pdf

Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A., & Hoving, C. (2013). A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of medical Internet research, 15*(4:e85), 1-17. http://doi.org/10.2196/jmir.1933.

Morgan, K. W. (Ed.) (1987). *Islam, the straight path: Islam interpreted by Muslims*. Delhi, India: Motilal Banarsidass Publishers.

Morrison, C. S., Richardson, B. A., Mmiro, F., Chipato, T., Celentano, D. D., Luoto, J., . . . Brown, J. M. (2007). Hormonal contraception and the risk of HIV acquisition. *AIDS, 21*(1), 85-95. https://www.doi.org/10.1097/QAD.0b013e3280117c8b

Morineau, G., Nugrahini, N., Riono, P., Girault, P., Mustikawati, D. E., & Magnani, R. (2011). Sexual risk taking, STI and HIV prevalence among men who have sex with men in six Indonesian cities. *AIDS and Behavior, 15*(5), 1033-1044.

Muhaimin, T., & Besral. (2011). HIV prevalence among pregnant women in eight provincial capitals in Indonesia in 2003-2010. *Makara Kesehatan, 15*(2), 93-100. https://doi/org/10.7454/msk.v15i2.943

Mulia, S. M. (2009). Women and Local Islamic Culture in Indonesia. Retrieved from http://www.crvp.org/book/Series03/IIID-6/chapter-13.htm

Mulia, S. M., & Cammack, M. E. (2007). Toward a just marriage law: empowering Indonesian women through a counter legal draft to the Indonesian compilation of Islamic law. *Islamic Law in Contemporary Indonesia: Ideas and Institutions*, 128-145.

Munro, J., & McIntyre, L. (2015). (Not) getting political: Indigenous women and preventing mother-to-child transmission of HIV in West Papua. *Culture, Health & Sexuality, 18*(2), 157-172. https://doi.org/10.1080/13691058.2015.1070436

Mutaqin, Z. Z. (2018). Culture, Islamic feminism, and the quest for legal reform in Indonesia. *Asian Journal of Women's Studies, 24*(4), 423-445.

Najmah, Fajar, N., & Sitorus, R. J. (2011). The effect of needle and syringe program on injecting drug users' use of non-sterile syringe and needle behaviour in Palembang, South Sumatera Province, Indonesia. *International Journal of Public Health Research, 1*(Special Issue), 193-198. Retrieved from http://journalarticle.ukm.my/3554/

Najmah, Davies, S. G., & Andajani S. (2017). HIV-positive mothers left behind. Retrieved from https://www.insideindonesia.org/hiv-positive-mothers-left-behind

Najmah. (2017, December 4). Hope of HIV positive mothers in Palembang : My child is free-HIV (Harapan ibu positif HIV di Palembang 'Aku ingin anakku bebas dari HIV'). *Sriwijaya Post.* Retrieved from http://palembang.tribunnews.com/2017/12/04/harapan-ibu-positif-hiv-di-palembang-aku-ingin-aanakku-bebas-dari-hiv

Najmah (participant). (2019, 23 August). 2019 AUT 3MT Competition Doctoral Finals-Najmah Usman "My baby deserves love, not HIV". [Video] Retrieved from https://www.youtube.com/watch?v=y4uebpiV2kQ

Najmah. (2018). *Honouring many forms of action: What we can do for better accessibility of PMTCT services.* Paper presented at the A colloqium on the intersections of culture, health, and sexuality, Dilman, Philiphines.

Najmah, Davies, S. G., & Andajani S. (2019). Getting married to a suspected bisexual man: A silent mode of HIV transmission among married women in Indonesia. *Indian Journal of Public Health & Development, 10*(7), 976-980. http://dx.doi.org/10.5958/0976-5506.2019.01705.4

Najmah, Davies, S. G., & Andajani, S. (2020). Wives and mothers and HIV. Retrieved from https://www.insideindonesia.org/wives-and-mothers-and-hiv

Najmah, Andajani, S., & Davies, S. G. (2020). Perceptions of and barriers to HIV testing among married women in Indonesia. *Sexual and Reproductive Health Matters (In process).*

Najmah, Sari, I., Purnama,, Kumalasari, T., Novia,, Davies, S., Graham,, & Andajani, S. (2017). *The Role of Education, Occupation, Place of Residence, Marital and Socioeconomic Status on HIV Knowledge among Women of Childbearing Age in South Sumatra, Indonesia.* Paper presented at the International Public Health Conference, Palembang, Sriwijaya University.

Najmah, Sari, I., Purnama,, Kumalasari, T., Novia,, Davies, S., Graham,, & Andajani, S. (2020). Factor influencing HIV knowledge among women of childbearing age in South Sumatra, Indonesia. *Malaysian Journal of Public Health Medicine, 20* (1), 150-159. doi: https://doi.org/10.37268/mjphm/vol.20/no.1/art.552

Narli, N. (1989). Review of a book Indonesian woman in focus: Past and present notions. *Journal of Souteast Asian Studies, 20*(1), 111-114. https://www.jstor.org/

Nesheim, S., Harris, L., & Lampe, M. (2013). Elimination of perinatal HIV infection in the USA and other high-income countries. *achievements and challenges, 8*(5), 447-456. https://insights.ovid.com/article/01222929-201309000-00013

Nisa, E. F. (2018). Social media and the birth of an Islamic social movement: ODOJ (One Day One Juz) in contemporary Indonesia. *Indonesia and the Malay World, 46*(134), 24-43. doi:https://doi.org/10.1080/13639811.2017.1416758

Nguyen, T. A., Oosterhoff, P., Hardon, A., Tran, H. N., Coutinho, R. A., & Wright, P. (2008). A hidden HIV epidemic among women in Vietnam. *BMC public health, 8*(37), 1-11. https://doi.org/10.1186/1471-2458-8-37

Nguyen, T. A., Oosterhoff, P., Ngoc, Y. P., Wright, P., & Hardon, A. (2008). Barriers to access prevention of mother-to-child transmission for HIV positive women in a well-resourced setting in Vietnam. *AIDS research and therapy, 5*(1), 1-12. https://doi.org/10.1186/1742-6405-5-7

Nguyen, T. A., Oosterhoff, P., Pham, Y. N., Hardon, A., & Wright, P. (2009). Health workers' views on quality of prevention of mother-to-child transmission and postnatal care for HIV-infected women and their children. *Human resources for health, 7*(39), 1-11. https://human-resources-health.biomedcentral.com/

Noone, J. H., & Stephens, C. (2008). Men, masculine identities, and health care utilisation. *Sociology of health & illness,, 30*(5), 14. https://doi.org/10.1111/j.1467-9566.2008.01095.x

Nugroho, A., Erasmus, V., Coulter, R. W., Koirala, S., Nampaisan, O., Pamungkas, W., & Richardus, J. H. (2018). Driving factors of retention in care among HIV-positive MSM and transwomen in Indonesia: A cross-sectional study. *PloS one, 13*(1:e0191255), 1-15. https://doi.org/10.1371/journal.pone.0191255

Nurmila, N. (2009). *Women, Islam and everyday Life*. London, UK: Routledge.

Nurmila, N. (2016). Social and religious construction of motherhood in Indonesia: Negotiating expectations of childbearing, family size, and governmental policies. In M. A. Pappano & D. M. Olwan (Eds.), *Muslim Mothering* (pp. 221-244). Canada, Canada: Demeter.

Nurmila, N., & Bennett, L. R. (2015). The sexual politics of polygamy in Indonesian marriages. In L. R. Bennett & S. G. Davies (Eds.), *Sex and sexualities in contemporary Indonesia: Sexual politics, health, diversity and representations* (pp. 69-85). London, UK: Routledge.

O'Brien, L., Shaffer, N., Sangrujee, N., & Abimbola, T. O. (2014). The incremental cost of switching from Option B to Option B+ for the prevention of mother-to-child transmission of HIV. *Bulletin of the World Health Organization, 92*(3), 162-170. http://dx.doi.org/10.2471/BLT.13.122523

O'Reilly, K. R., Kennedy, C. E., Fonner, V. A., & Sweat, M. D. (2013). Family planning counseling for women living with HIV: A systematic review of the evidence of effectiveness on contraceptive uptake and pregnancy incidence. *BMC public health, 13*(1), 935. https://doi.org/10.1186/1471-2458-13-935

Oktavia, M., Alban, A., & Zwanikken , P. A. (2012). *A qualitative study on HIV positive women experience in PMTCT program in Indonesia*. Paper presented at the 17th International Symposium on HIV and Emerging Infectious Diseases (ISHEID), Marseilla, France.

Oosterhoff, P., Hardon, A. P., Nguyen, T. A., Pham, N. Y., & Wright, P. (2008). Dealing with a positive result: Routine HIV testing of pregnant women in Vietnam. *AIDS care, 20*(6), 654-659. https://doi.org/10.1080/09540120701687026

Ostrach, B., & Singer, M. (2012). At special risk: Biopolitical vulnerability and HIV/STI syndemics among women. *Health Sociology Review, 21*(3), 258-271.

Palembang PHO. (2018). *Health profile of Palembang in 2017*. Palembang, Indonesia: Palembang PHO. Retrieved from http://dinkes.palembang.go.id/tampung/dokumen/dokumen-157-281.pdf.

Panditrao, M., Darak, S., Kulkarni, V., Kulkarni, S., & Parchure, R. (2011). Socio-demographic factors associated with loss to follow-up of HIV-infected women attending a private sector PMTCT program in Maharashtra, India. *AIDS care, 23*(5), 593-600. https://doi.org/10.1080/09540121.2010.516348

Pappano, M. A., & M. Olwan, D. (Eds.). (2016). *Muslim mothering: Global histories theories, and practices*. Canada, Canada: Demeter Press.

Parker, L., & Creese, H. (2016). The stigmatisation of widows and divorcees (janda) in Indonesian society. *Indonesia and the Malay World, 44*(128), 1-6. https://doi.org/10.1080/13639811.2015.1111647

Parker, L., Riyani, I., & Nolan, B. (2015). The stigmatisation of widows and divorcees (janda) in Indonesia, and the possibilities for agency. *Indonesia and the Malay World, 44*(128), 19-27. https://doi.org/10.1080/13639811.2016.1111677

Pendse, R., Gupta, S., Yu, D., & Sarkar, S. (2016). HIV/AIDS in the South-East Asia region: Progress and challenges. *Journal of virus eradication, 2*(Suppl 4), 1-6. https://www.ncbi.nlm.nih.gov/

Pertiwi, K., & Yulindrasari, H. (2018). Tentang Dharma Wanita (Bagian 1): Jejak pengukuhan wacana perempuan. Retrieved from https://kumparan.com/birokrat-menulis/tentang-dharma-wanita-bagian-1-jejak-pengukuhan-wacana-perempuan-1539834774705654321

Phanuphak, N., & Phanuphak, P. (2016). History of the prevention of mother-to-child transmission of HIV in Thailand. *Journal of virus eradication, 2*(2), 107-109. https://www.ncbi.nlm.nih.gov/

Philips, S. U. (2001). Gender ideology: Cross-cultural aspects. *International Encyclopedia of the Social & Behavioral Sciences*, 6016-6020. https://doi.org/10.1016/B0-08-043076-7/03962-0

Pisani, E. (2010). *The wisdom of whores: Bureaucrats, brothels and the business of AIDS*. New York, NY: W.W Norton & Co.

Platt, M., Davies, S. G., & Bennett, L. R. (2018). Contestations of gender, sexuality and morality in contemporary Indonesia: Taylor & Francis.

Platt, M. (2017). *Marriage, gender and Islam in Indonesia*. New York, NY: Routledge

Ponic, P., Reid, C., & Frisby, W. (2010). Cultivating the power of partnerships in feminist participatory action research in women's health. *Nursing inquiry, 17*(4), 324-335. https://doi.org/10.1111/j.1440-1800.2010.00506.x

Praptoraharjo, I., Suharni, Pudhiati, S. R., Dewi, E. H., & Safika, I. (2016a). *HIV-AIDS policy and health system in Indonesia - A document review* Retrieved from http://www.kebijakanaidsindonesia.net/id/hasil-penelitian/1393-kajian-dokumen-kebijakan-hiv-aids-dan-sistem-kesehatan-di-indonesia

Praptoraharjo, I., Suharni, Pudhiati, S. R., Dewi, E. H., & Safika, I. (2016b). *A model of HIV prevention through sexual transmission: In primary health service puskesmas and the coverage* Retrieved from http://www.kebijakanaidsindonesia.net/id/hasil-penelitian/1393-kajian-dokumen-kebijakan-hiv-aids-dan-sistem-kesehatan-di-indonesia

Priest, P. (2017). HIV trends in New Zealand. Retrieved from https://www.bodypositive.org.nz/documents/TreatmentsUpdate_PPT/2017/Patricia_Priest.html

Prihatini, E. S. (2018a). Measuring women' s chances of winning in Indonesia's regional elections*April 24, 2018* Retrieved from https://theconversation.com/measuring-womens-chances-of-winning-in-indonesias-regional-elections-95294

Prihatini, E. S. (2018b). Women's electability rises in Indonesia's 2018 local elections*August 10, 2018* Retrieved from https://theconversation.com/womens-electability-rises-in-indonesias-2018-local-elections-101274

Primastika, W. (2019, Juli 26). Without a public Insurance (BPJS), the cost for delivery is so expensive (*Tanpa jaminan BPJS, biaya melahirkan bisa memberatkan*). *Tirto*. Retrieved from https://tirto.id/tanpa-jaminan-bpjs-biaya-melahirkan-bisa-memberatkan-cPM3

Rae, J., & Green, B. (2016). Portraying reflexivity in health services research. *Qualitative health research, 26*(11), 1543-1549. https://www.doi.org/10.1177/1049732316634046

Rahmalia, A., Wisaksana, R., Meijerink, H., Indrati, A. R., Alisjahbana, B., Roeleveld, N., . . . Crevel, R. (2015). Women with HIV in Indonesia: Are they bridging a concentrated epidemic to the wider community? *BMC Research Notes, 8*(1), 1. https://www.doi.org/10.1186/s13104-015-1748-x

Randolph, M. E., Pinkerton, S. D., Bogart, L. M., Cecil, H., & Abramson, P. R. (2007). Sexual pleasure and condom use. *Archives of sexual behavior, 36*(6), 844-848. https://www.ncbi.nlm.nih.gov/

Regmi, K., & Naidoo, J. (2013). Understanding the processes of writing papers reflectively. *Nurse researcher, 20*(6), 33-39. https://www.ncbi.nlm.nih.gov/

Reid, C., & Frisby, W. (2008). Continuing the journey: Articulating dimensions of Feminist Participatory Action Research (FPAR). In P. Reason & H. Bradbury (Eds.), *Sage handbook of action research: Participative inquiry and practice* (Vol. 2, pp. 93-105). London, UK: SAGE.

Reinharz, S. (1992). The principles of feminist research: A matter of debate. In K. C & S. D (Eds.), *The knowledge explosion: Generation of feminist scholarship*. New York, NY: NY. Teacher's college press.

Reinharz, S., & Davidman, L. (1992). *Feminist methods in social research*. Oxford, UK: Oxford University Press.

Ricklefs, M. C. (2008). *A History of Modern Indonesia since c. 1200*. Stanford, CA: Stanford University Press.

Riono, P., & Jazant, S. (2004). The current situation of the HIV/AIDS epidemic in Indonesia. *AIDS Education and Prevention, 16*(Supplement A), 78-90. https://www.doi.org/10.1521/aeap.16.3.5.78.35531

Risal, A., & Gunawan, J. (2018). Men, masculinities and HIV/AIDS in Indonesia. *Belitung Nursing Journal, 4*(1), 2. https://www.doi.org/10.33546/bnj.403

Riyarto, S., Hidayat, B., Johns, B., Probandari, A., Mahendradhata, Y., Utarini, A., . . . Flessenkaemper, S. (2010). The financial burden of HIV care, including antiretroviral therapy, on patients in three sites in Indonesia. *Health policy and planning, 25*(4), 272-282. https://www.doi.org/10.1093/heapol/czq004

Robinson. (2011). Role playing. In Lewis Beckl, B. A. M, & T. F. Liao (Eds.), *The SAGE Enscyclopedia of Social Science Research Methods*. New York, NY: Sage Publication.

Robinson, K. (2000). Indonesian women: From Orde Baru to Reformasi. In L. Edwards & M. Roces (Eds.), *Women in Asia: Tradition, Modernity, and Globalisation* (pp. 139-169). Michigan, US: University of Michigan Press,.

Rubin, H. J., & Rubin, I. s. (2012). *Qualitative interviewing, the art of hearing data*. Los Angeles, CA: SAGE.

Ryan-flood, Roisin, G., & Rosalind (Eds.). (2010). *Secrecy and silence in the research process: Feminist reflection*. London, UK: Routledge.

Sakti, G. M. (2015). *The policy of mother to child trannsmission program*. Retrieved from Jakarta, Indonesia.

Saldana, J. (2016). *The coding manual for qualitative researchers* (J. Seaman Ed.). Los Angeles, CA: SAGE.

Samuels, A. (2018). “This path Is full of thorns”: Narrative, subjunctivity, and HIV in Indonesia. *Ethos, 46*(1), 95-114. doi:https://www/doi.org/10.1111/etho.12194

Sanders, E. B.-N., & Stappers, P., Jan,. (2012). *Convivial toolbox, generative research for the front end of design*. Amsterdam, Netherland: BIS.

Sangaramoorthy, T., Jamison, A., & Dyer, T. (2017). Intersectional stigma among midlife and older Black women living with HIV. *Culture, Health & Sexuality, 19*(12), 1329-1343.

Saunders, M., Lewis, P., & Thornhill, A. (2012). *Research methods for business students* (6th ed.). Harlow, London, UK: Pearson.

Skeldon, R. (2000). *Population mobility and HIV vulnerability in South East Asia: An assessment and analysis*. Thailand: UNDP South East Asia HIV and Development Project.

Schneider, H., Blaauw, D., Gilson, L., Chabikuli, N., & Goudge, J. (2006). Health systems and access to antiretroviral drugs for HIV in Southern Africa: Service delivery and human resources challenges. *Reproductive health matters, 14*(27), 12-23.

Sears, J. L. (Ed.) (1999). *Fantasizing the feminine in Indonesia*. Durham, UK: Duke University Press.

Senarak, W., Chirawatkul, S., & Markovic, M. (2006). Health promotion for middle-aged Isan women, Thailand: A participatory approach. *Asian Pacific Journal of Cancer Prevention, 7*(1), 55-9.

Setyawati, L. (2008). Adat, Islam, and womanhood in the reconstruction of Riau Malay identity. In S. Blackburn, B. J. Smith, & S. Syamsiyatun (Eds.), *Indonesian Islam in a new era: How women negotiate in their Muslim identities* (pp. 191). Clayton, Victoria: Monash University Press.

Silverman, D. (2014). *Interpreting qualitative data*. Thousand oaks, UK: SAGE.

Sollai, S., Noguera-Julian, A., Galli, L., Fortuny, C., Deyà, Á., de Martino, M., & Chiappini, E. (2015). Strategies for the prevention of mother to child transmission in Western countries: An update. *The Pediatric Infectious Disease Journal, 34*(5), S14-S30. https://www.doi.org/10.1097/INF.0000000000000661

South Sumatra Governor. (2002). *South Sumatra regulation number 13 year of 2002 about elimination of immoral behaviour in South Sumatra Province (Perda Propinsi Sumatera Sealtan no 13 tahun 2001 tentang Pemberantasan maksiat di propinsi Sumatra Selatan)*. Palembang, Indonesia: South Sumatra Governor.

South Sumatra PHO. (2017). *Situation analysis of HIV/AIDS in South Sumatra 2017*. Palembang, Indonesia: South Sumatra PHO.

South Sumatra PHO. (2018). *HIV-AIDS and sexually transmitted diseases programmes in PHO in South Sumatra*. Palembang, Indonesia: South Sumatra PHO.

Spagnoletti, B. R. M., Bennett, L. R., Kermode, M., & Wilopo, S. A. (2018). 'I wanted to enjoy our marriage first… but I got pregnant right away': A qualitative study of family planning understandings and decisions of women in urban Yogyakarta, Indonesia. *BMC pregnancy and childbirth, 18*(1), 353. doi:https://www.doi.org/10.1186/s12884-018-1991-y

Statista. (2019). Literacy rate in Indonesia 2016. Retrieved from https://www.statista.com/statistics/572721/literacy-rate-in-indonesia/

Statistics Indonesia, National Population and Family Planning Board, MOH, & Measure DHS ICF International. (2013). *Indonesian Demographic Health Survey (IDHS) in 2012*. Jakarta, Indonesia: Statistics Indonesia Retrieved from https://dhsprogram.com/pubs/pdf/FR275/FR275.pdf.

Statistics of Indonesia. (2016). *Potray of education in Indonesia: Statistics of education 2016 (Potret pendidikan Indonesia: Statistik pendidikan 2016)*. Jakarta, Indonesia: Statistics of Indonesia, Retrieved from https://media.neliti.com/media/publications/48188-ID-potret-pendidikan-indonesia-statistik-pendidikan-indonesia.pdf

Statistics of Indonesia. (2018). *Indonesia in numbers*. Jakarta, Indonesia: Statistics of Indonesia, Retrieved from http://www.bps.go.id/.

Statistics of Palembang. (2018a). *Indicators of education in Palembang (Indikator pendidikan kota Palembang)*. Palembang, Indonesia: Statistics of Palembang Retrieved from https://palembangkota.bps.go.id/statictable/2015/09/30/27/indikator-pendidikan-kota-palembang.html, .

Statistics of Palembang. (2018b). *Palembang in figures*. Palembang, Indonesia: Statistics of Palembang Retrieved from https://palembangkota.bps.go.id/publication/2018/08/16/b3fad0b55076a742da4af61b/kota-palembang-dalam-angka-2018.html.

Statistics of Palembang. (2018c). *Statistic on labour in Palembang (Statistik ketenagakerjaan kota Palembang)*. Palembang, Indonesia: Statistics of Palembang (BPS) Retrieved from https://palembangkota.bps.go.id/publication/.

Suharni, Hersumpana, Lily, C., Perwira, I., Safika, i., Praptoraharjo, I., s, . . . Dewi, E. H. (2016). *Notes for HIV & AIDS policy and programmes in Indonesia (Catatan atas Kebijakan dan Program HIV & AIDS di Indonesia)* Retrieved from https://www.kebijakanaidsindonesia.net/id/dokumen-kebijakan/download/5-penelitian-research/1005-catatan-atas-kebijakan-dan-program-hiv-aids-di-indonesia

Sukmaningrum, E. (2015). *HIV disclosure experiences among women with HIV/AIDS in Jakarta, Indonesia*. (Doctoral dissertation), University of Illinois Chicago, Illinois. Retrieved from https://www.indigo.lib.uic.edu/handle/10027/19557

Suryakusuma, I., Julia,. (1999). The State and Sexuality in New Order Indonesia. In J. L. Sears (Ed.), *Fantasizing the feminine in Indonesia* (pp. 92-119). Durham&London: Duke University Press.

Suryakusuma, I., Julia,. (2011). *State Ibuism-The social construction of womanhood in New Order Indonesia* (T. L. a. J. Suryakusuma Ed.). Bandung: Komunitas Bambu.

Tambunan, A. (2015, December 1). I am Positive (Saya Positif). *Kompas*. Retrieved from https://www.kompas.com/

Tangcharoensathien, V., Patcharanarumol, W., Ir, P., Aljunid, S. M., Mukti, A. G., Akkhavong, K., . . . Mills, A. (2011). Health-financing reforms in Southeast Asia: Challenges in achieving universal coverage. *The Lancet, 377*(9768), 863-873. https://www.ncbi.nlm.nih.gov/

Temple, B. (2008). Translatability. In L.M.Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 890). Thousand Oaks, UK: SAGE.

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In Carla Willig & Wendy Stainton Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 17-37). Thousand Oaks: SAGE.

The Global Fund. (2018). Indonesia and Global Fund unveil new grants. Retrieved from https://www.theglobalfund.org/en/news/2018-02-13-indonesia-and-global-fund-unveil-new-grants/

The Noble Qur’an (n.d.). Retrieved from https://quran.com/search?q=An-nisa

The World Bank. (2018). Overview the World Bank in Indonesia: Context. Retrieved from http://www.worldbank.org/en/country/indonesia/overview

Thisyakorn, U. (2017). Elimination of mother-to-child transmission of HIV: Lessons learned from success in Thailand. *Paediatrics and international child health, 37*(2), 99-108. https://www.doi.org/10.1080/20469047.2017.1281873

Thompson, N. (2012). *Anti-discriminatory practice* New York, NY: Palgrave MacMillan.

Thorne, C. (2014). Newly infected mothers are more likely pass HIV on to babies. *February 2014,*. Retrieved from The Conversation website: https://theconversation.com/newly-infected-mothers-are-more-likely-to-pass-hiv-on-to-babies-23578

Triansyah, Y. (2015, December 1). Housewives dominates HIV-AIDS patients in South Sumatera (Ibu Rumah Tangga Mendominasi Penderita HIV/AIDS di Sumsel). *Sriwijaya Post.* Retrieved from http://palembang.tribunnews.com/

Tudor Car, L., van-Velthoven, M. H., Brusamento, S., Elmoniry, H., Car, J., Majeed, A., & Atun, R. (2011). Integrating prevention of a mother to a child HIV transmission (PMTCT) programmes with other health services for preventing HIV infection and improving HIV outcomes in developing countries. *The Cochrane Library, 15*(6 (CD008741)), 1-10. https://doi.org/10.1002/14651858.CD008741.pub2

Turan, J. M., & Nyblade, L. (2013). HIV-related stigma as a barrier to achievement of global PMTCT and maternal health goals: a review of the evidence. *AIDS and Behavior, 17*(7), 2528-2539. https://doi.org/10.1007/s10461-013-0446-8

Turner, S. G., & Maschi, T. M. (2015). Feminist and empowerment theory and social work practice. *Journal of Social Work Practice, 29*(2), 151-162. https://doi.org/10.1080/02650533.2014.941282

UNAIDS. (2013). *HIV in Asia and Pacific* Retrieved from https://www.unaids.org/sites/default/files/media_asset/2013_HIV-Asia-Pacific_en_0.pdf

UNAIDS. (2015). *UNAIDS terminology guidelines* Retrieved from http://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf

UNAIDS. (2016). *Children and HIV: Fact sheet*. Retrieved from https://www.unaids.org/sites/default/files/media_asset/FactSheet_Children_en.pdf

UNAIDS. (2017). *Start free stay free AIDS free 2017 Progress Report* Retrieved from http://www.unaids.org/sites/default/files/media_asset/JC2923_SFSFAF_2017progressreport_en.pdf

UNAIDS. (2018). *Miles to go: Closing gaps breaking barriers righting injustices* Retrieved from http://www.unaids.org/sites/default/files/media_asset/miles-to-go_en.pdf

UNAIDS. (2019). *UNAIDS data 2018* Retrieved from https://www.unaids.org/sites/default/files/media_asset/unaids-data-2018_en.pdf

UNAIDS. (2020). *Country Factsheets in Indonesia: HIV and AIDS Estimates in 2018.* Retrieved from https://www.unaids.org/en/regionscountries/countries/indonesia

UNICEF. (2018). *Children, HIV and AIDS: Global and regional snapshots*. Retrieved from https://data.unicef.org/resources/children-hiv-and-aids-global-and-regional-snapshots/

United Nations. (2000). United Nations millennium declaration. Retrieved from https://www.un.org/millennium/declaration/ares552e.pdf

UNWOMEN. (2019). *Progress of the world's women 2019-2020: Families in a changing world* Retrieved from https://www.unwomen.org/-/media/headquarters/attachments/sections/library/publications/2019/progress-of-the-worlds-women-2019-2020-en.pdf?la=en&vs=3512

Van de Perre, P., Tylleskär, T., Delfraissy, J.-F., & Nagot, N. (2013). How evidence based are public health policies for prevention of mother to child transmission of HIV? *BMJ: British Medical Journal, 346,* 20-21. https://www.bmj.com/

Ventola, C. L. (2014). Social media and health care professionals: Benefits, risks, and best practices. *Pharmacy and Therapeutics, 39*(7), 491. https://www.ncbi.nlm.nih.gov/

Vlekke, B. H. M. (2008). *Nusantara: Sejarah Indonesia (Nusantara: The History of Indonesia)*: Kepustakaan Populer Gramedia.

Wallerstein, N. (2006). *What is the evidence on effectiveness of empowerment to improve health?* Retrieved from http://www.popline.org/node/175634

Waluyo, A., Culbert, G. J., Levy, J., & Norr, K. F. (2015). Understanding HIV-related stigma Among Indonesian nurses. *Journal of The Association Of Nurses In AIDS Care JANAC, 26*(1), 11. https://www.doi.org/10.1016/j.jana.2014.03.001

Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: Portraits of participation. *Health Education & Behavior, 21*(2), 171-186. https://www.doi.org/10.1177/109019819402100204

Weber, L., & Castellow, J. (2012). Feminist research and activism to promote health equity. In S. N. Hesse-Biber (Ed.), *Handbook of feminist research: Theory and praxis* (Vol. 2, pp. 434-454). Los Angeles, CA: SAGE.

Weller, S. C., & Davis-Beaty, K. (2002). Condom effectiveness in reducing heterosexual HIV transmission. *Cochrane database of systematic reviews, 1*(CD003255), 1-11. https://doi.org/10.1002/14651858.CD003255

White, S., & Anshor, M. U. (2008). Islam and gender in contemporary Indonesia: Public discourses on duties, rights, and morality. In Greg Fealy & Sally White (Eds.), *Expressing Islam: Religious life and politics in Indonesia*. Singapore, Singapore: Institute of Souteast Asian Studies Singapore

WHO. (1986). The Ottawa charter for health promotion. Retrieved from https://www.who.int/healthpromotion/conferences/previous/ottawa/en/index1.html

WHO. (1998). *Health promotion glossary* (pp. 1-36). Retrieved from https://www.who.int/healthpromotion/about/HPR Glossary 1998.pdf

WHO. (2002). *25 questions and answers on health and human rights* Retrieved from https://www.who.int/hhr/information/25 Questions and Answers on Health and Human Rights.pdf

WHO. (2006). *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants in resource-limited settings: towards universal access* Retrieved from http://www.who.int/hiv/pub/guidelines/pmtct/en/index.html

WHO. (2007). *Prevention of Mother-To-Child Transmission (PMTCT)* In WHO (Series Ed.) *Briefing Note October 1st, 2007* Retrieved from https://www.who.int/hiv/pub/toolkits/PMTCT HIV Dept brief Oct 07.pdf

WHO. (2010). *PMTCT strategic vision 2010-2015 Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals* Retrieved from https://www.who.int/hiv/pub/mtct/strategic_vision.pdf

WHO. (2012). *HIV/AIDS in the South-East Asia Progress Report 2011* Retrieved from http://www.searo.who.int/entity/hiv/documents/hiv-aids_in_south-east_asia.pdf

WHO. (2013). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection Recommendations for a public health approach* Retrieved from https://www.who.int/hiv/pub/guidelines/arv2013/en/

WHO. (2016). *Health workforce requirements for universal health coverage and the Sustainable Development Goals.(Human Resources for Health Observer, 17)* Retrieved from https://apps.who.int/iris/bitstream/handle/10665/250330/9789241511407-;jsessionid=6561BD068FDC8765D78AEE1D4406E488?sequence=1

WHO. (2016). *Guidelines on HIV self-testing and partner notification: supplement to consolidated guidelines on HIV testing services*. Geneva: World Health Organization.

WHO. (2018). Malaysia eliminates mother-to-child transmission of HIV and syphilis. Retrieved from http://www.who.int/westernpacific/news/detail/08-10-2018-malaysia-eliminates-mother-to-child-transmission-of-hiv-and-syphilis

WHO. (2019a). Accessability. Retrieved from https://www.who.int/gender-equity-rights/understanding/accessibility-definition/en/

WHO. (2019b). Prevention of mother-to-child transmission (PMTCT). Retrieved from https://www.who.int/gho/hiv/epidemic_response/PMTCT_text/en/

WHO, & MoH. (2017). *State of health inequality: Indonesia Interactive visualization of health data* Retrieved from https://apps.who.int/iris/bitstream/handle/10665/259685/9789241513340-eng.pdf;jsessionid=9FADFCD87AB12BAB537C30D48E7C743A?sequence=1

WHO, & UNAIDS. (2013). *Guidelines for assessing the utility of data from prevention of mother-to-child transmission (PMTCT) programmes for HIV sentinel surveillance among pregnant women* Retrieved from https://apps.who.int/iris/bitstream/handle/10665/85512/9789241505611_eng.pdf?sequence=1

WHO, & UNAIDS. (2015). *Guidelines conducting HIV surveillance based on routine programme data among pregnant women attending antenatal clinics* Retrieved from https://apps.who.int/iris/bitstream/handle/10665/197864/9789241509725_eng.pdf;jsessionid=F0413CF46379F8788E0E6F0167642779?sequence=1

WHO, & UNICEF. (2016). *Guideline Update on HIV and Infant Feeding: the duration of breastfeeding and support from health services to improve feeding practices among mothers living with HIV* Retrieved from https://www.who.int/nutrition/publications/hivaids/guideline_hiv_infantfeeding_2016/en/

Wibawa, S. W. (2017). A housewife (Ibu Rumah Tangga) is more susceptible to get infected HIV than sex worker, Why is this condition happen (Kok bisa)? *KOMPAS*. Retrieved from https://sains.kompas.com/read/2017/12/01/170500023/ibu-rumah-tangga-lebih-rentan-terinfeksi-hiv-daripada-psk-kok-bisa-

Woodward, M. (2010). *Java, Indonesia and Islam* (Vol. 3). London, NY: Springer Science & Business Media.

World Atlas. (2015). Where Is Palembang, Indonesia? Retrieved from https://www.worldatlas.com/as/id/ss/where-is-palembang.html

World Bank. (2019). Children (ages 0-14) newly infected with HIV. Retrieved from https://data.worldbank.org/indicator/SH.HIV.INCD.14?end=2017&locations=ID&name_desc=false&start=1990&view=chart

Wormser, P. (2014). The spread of Islam in Asia through trade and Sufism (ninth–nineteenth centuries). In B. S. Turner & O. Salemink (Eds.), *Routledge handbook of religions in Asia*. London, UK,: Routledge.

Wu, J., Meng, Z., Xu, J., Lei, Y., Jin, L., Zhong, P., . . . Su, B. (2013). New emerging recombinant HIV-1 strains and close transmission linkage of HIV-1 strains in the Chinese MSM population indicate a new epidemic risk. *PloS One, 8*(1 (e54322)), 1-8. https://doi.org/10.1371/journal.pone.0054322

Wulandari, L. P. L., Lubis, D. S., Widarini, P., Widyanthini, D. N., Wirawan, I. M. A., & Wirawan, D. N. (2019). HIV testing uptake among pregnant women who attending private midwife clinics: challenges of scaling up universal HIV testing at the private sectors in Indonesia. *The International Journal of Health Planning and Management.*

Yayasan Spritia. (2014). History of HIV in Indonesia. Retrieved from http://spiritia.or.id/art/bacaart.php?artno=1040.

Yoshihama, M., & Carr, E. S. (2002). Community Participatin Reconsidered: Feminist Participatory Action Research with Hmong women. *Journal of Community Practice 10(4), 10*(4), 18. doi:https://doi.org/10.1300/J125v10n04_06.

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 AUTEC is notified of any adverse events or if the research does not commence. AUTEC 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.

AUTEC 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,

K O'Connor

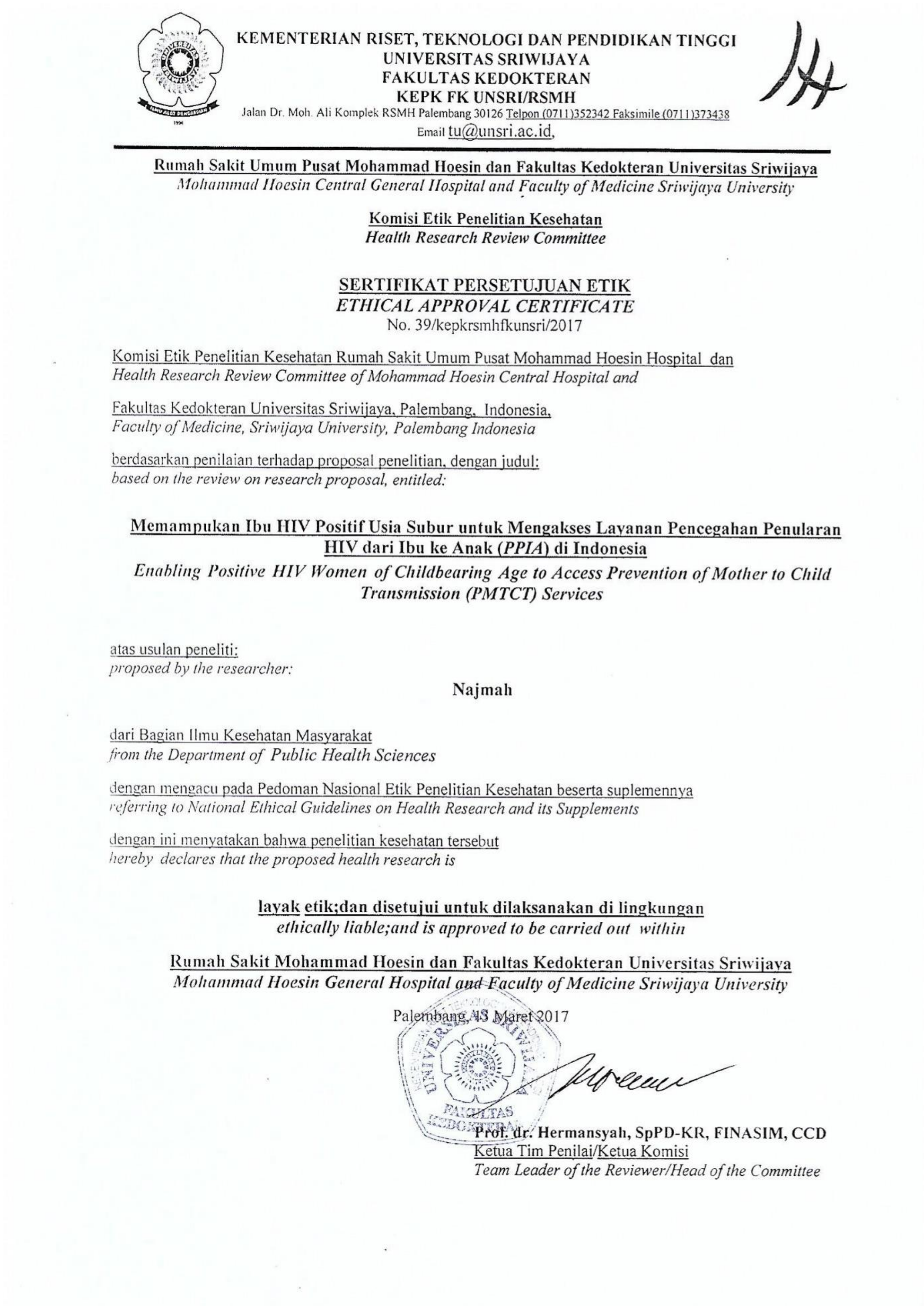
Kate O'Connor

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 Telpon (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 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 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 AUTEC, 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.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 warohmatullahiwabarokatuh

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 saya 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 disebarkan oleh LSM terkait HIV dan staf dari Dinas Kesehatan Kota Palembang ke partisipan yang potential 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 penelitan 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 risko 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 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 mengekspersikan 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 trankrip, 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 Departemen Ilmu Sosial di Universitas Auckland Teknologi dengan maksimal penyimpanan 6 tahun dari selesainya projek 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 hingga dua minggu untuk memutuskan apakah anda bersedia berpartisipasi dalam penelitian ini. Anda bisa mengirim sms atau emaik 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 AUTEC, 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 AUTEC 17/22

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

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 iformed 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 additon, 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 AUTEC, 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 warohmatullahiwabarokatuh

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 saya 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 disebarkan oleh LSM terkait HIV dan staf dari Dinas Kesehatan Kota Palembang ke partisipan yang potential 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 penelitan 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 risko apa dalam penelitian ini?

Anda mungkin mengalami tingkat ketidaknyamana 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 ketidaknyaman 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 mengekspersikan 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 trankrip, metode visual, catatan lapangan, dan hasil penelitian lainnya hanya kepada pembimbing disertasi saya.

Semua dokumen terhasil rekaman interview, dan hasil transkrip interview akan disimpan di komputer saya yang memiliki pasword. 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 projek 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 hingga dua minggu untuk memutuskan apakah anda bersedia berpartisipasi dalam penelitian ini. Anda bisa mengirim sms atau emaik 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 terkati 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

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 tanggall 7 Maret 2017 dengan nomor referensi AUTEC 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 week 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 AUTEC, 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*, AUTEC 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 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 saya 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) menawarakan 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 ketersedian 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, teramsuk pemahaman mereka tentang PPIA, kendala dalam mengakses PPIA, faktor faktor yang bisa memotivasi mereka untuk akses ke PPIA dan ide bagaimana meningkatakan 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 risko 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 ketidaknyaman dan resiko ini bisa diminimalisir?

Saya akan berusaha membentu 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 trankrip, 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 projek 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 bekerj

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 AUTEC, 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 AUTEC 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 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 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 AUTEC, 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*, AUTEC 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 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 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 saya 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) menawarakan 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 ketersedian 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, teramsuk pemahaman mereka tentang PPIA, kendala dalam mengakses PPIA, faktor faktor yang bisa memotivasi mereka untuk akses ke PPIA dan ide bagaimana meningkatakan daya akses mereka terhadap PPIA. Kegiatan ini akan dikombinasi dengan metode visuzl, seperti menggambar, peta pikiran dan koalase atau klipping atau juga melalui pantun dan cara tradisional Palembang lainnya.

Ketidaknyamanan dan risko apa dalam penelitian ini?

N/A

Bagaimana ketidaknyaman 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 trankrip, 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 projek 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 AUTEC, 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

Disetujui oleh Komite Etik Universitas Auckland Teknologi pada tanggal 7 Maret 2017 dengan nomor referensi AUTEC 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
AUTEC 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, sediri 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 pekrjaan 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 :

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

Catatan: Partisipan harus memegang kopi dari formulir ini

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

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*, AUTEC 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 Indonesia

Pembimbing Disertas : ***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 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 AUTEC 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 AUTEC 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 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 identitas sesame 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 AUTEC 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

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

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?

<u>(Part 3) Accessing prevention of mother-to-child transmission of HIV services?</u>

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 looks 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 sharetany 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/ 911 /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 Pengambila 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

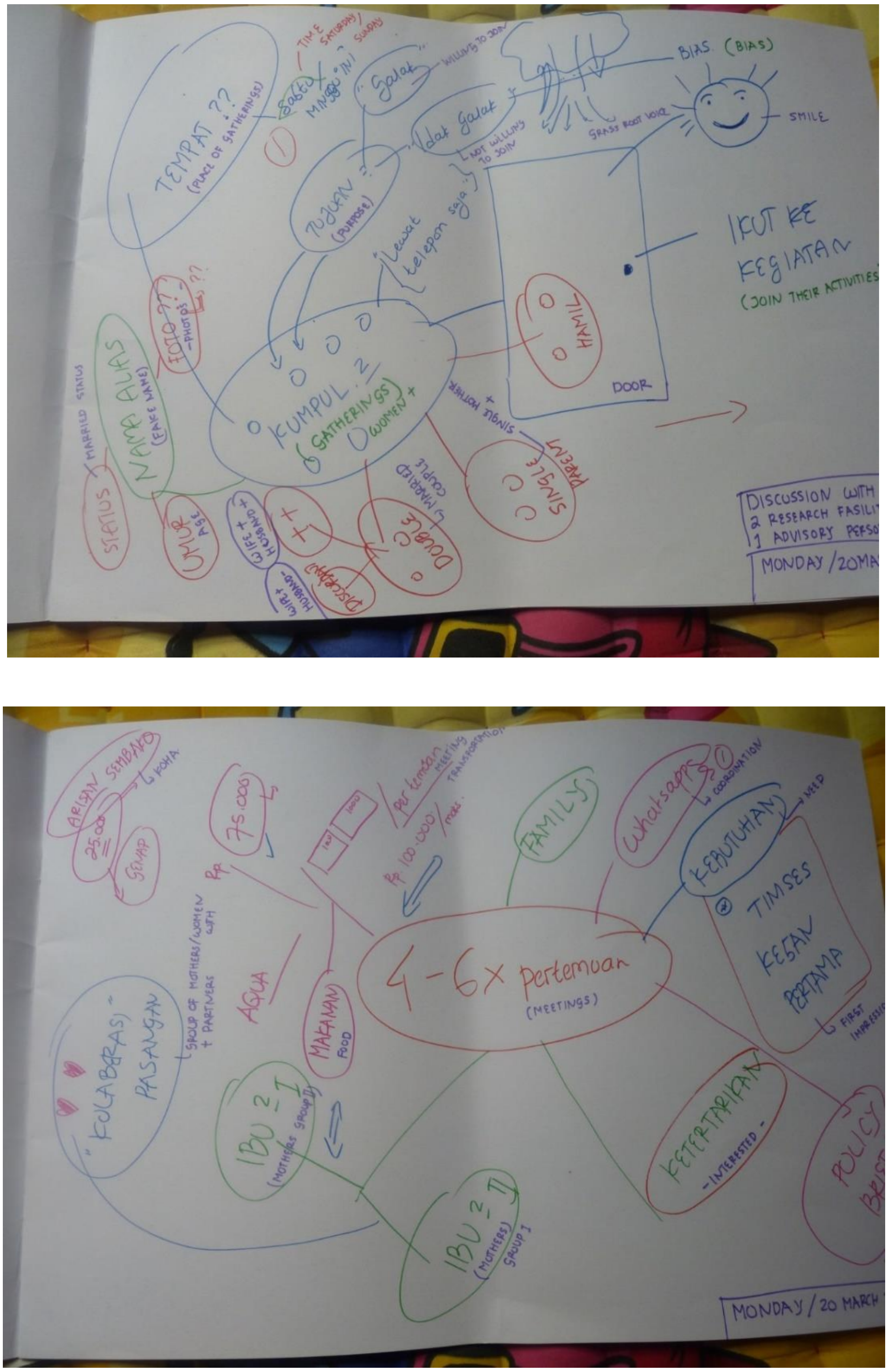
Aim of Study	Methods and Participants	Strengths**	Limitations
To create a space for children from divorced families to reconstruct their new lives (or rainbows) and be guided toward resilience and hope. Carr (2003)	Narrative study; Qualitative research paradigm of FPAR Discourse Analysis Reflection Process 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; Mclntyre, 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
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. (Botha & Hay, 2016)	Feminist PAR as methodology First Phase: providing 12 Hmong women with limited English, with participatory workshops on photovoice[77] methods Second Phase: providing eight Hmong women fluent in English, with monthly workshops to improve their organisational skills in building a non-profit organisation	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.	Translation in the study could have resulted in misinterpretation.
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 & Ponic, 2011)	Used photovoice methods 19 Ixil women	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	Translation in the study could have resulted in misinterpretation

---

[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.2: Mindmaps of fieldwork planning with Research Facilitators



Appendix figure D.1: Mind map of fieldwork planning with research facilitators

The figures depict the recruitment process of HIV-positive women in Palembang and some preparation of FGDs and inteviews for the women (from an informal discussion with my research facilitators, 20 March 2017)

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 AUTEC 17/22
Disetujui oleh Komite Etik Universitas Sriwijaya 13 Maret 2017, dengan No. 39/kepkrsmhfkunsri/2017

WAKTUNYA PEREMPUAN / IBU POSITIF
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 AUTEC 17/22
Disetujui oleh Komite Etik Universitas Sriwijaya 13 Maret 2017, dengan No. 39/kepkrsmhfkunsri/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 Palembangese 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

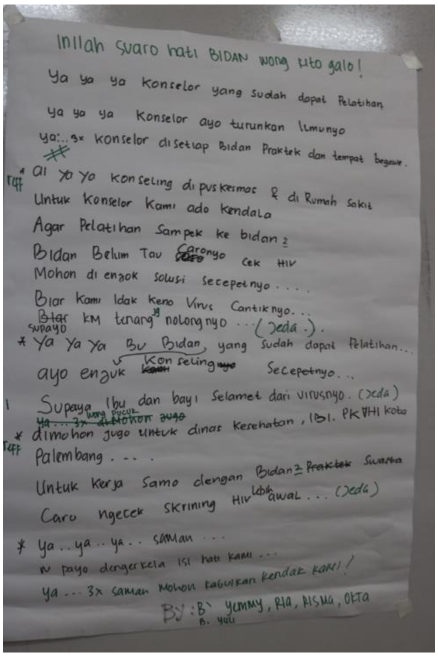
D.a.3: Transcript of Dr Zizi in Indonesia

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 berhapan 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=DlGVTaZnT_o).



Inilah suaro hati BIDAN wong kito galo!
Ya ya ya konselor yang sudah dapat pelatihan
ya ya ya konselor ayo turunkan ilmunyo
ya:..3x konselor di setiap Bidan Praktek dan tempat begawe.
#
reff *ai ya ya konseling di puskesmas & di Rumah sakit
Untuk konselor kami ado kendala
Agar pelatihan sampek ke bidan2
Bidan Belum Tau ~~caro~~ caronyo cek HIV
Mohon di enjok solusi secepetnyo....
Biar kami idak keno virus cantiknyo...
~~Biar~~ supayo km tenang yg nolongnyo ...(Jeda.).
* Ya ya ya Bu Bidan, yang sudah dapat pelatihan...
ayo enjuk ~~kami~~ konseling ~~nyo~~ secepetnyo...
Supaya Ibu dan bayi selamet dari virusnyo. (Jeda)
~~ya...3x dimohon jugo~~ wong pucuk
* dimohon jugo untuk dinas kesehatan, IBI. PKVHI kota
reff Palembang....
Untuk kerja samo dengan Bidan2 ~~Praktek~~ Swasta
Caro ngecek skrining HIV lebih awal... (Jeda)
* ya..ya..ya.. saman...
payo dengerkela isi hati kami...
ya...3x saman mohon kabulkan kendak kami!
By: B' yemmy, Ria, Risma, Okta
B. yuli

***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 dienjuk solusi secepatnya
Biar kami idak keno virus cantiknyo
Biar kami tenang nolongnyo (Jeda)

***Ya ya ya Bu bidan yang sudah dapat pelatihan*
Ayo enjuk konseling secepatnyo
Supayo 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	First verse
Ibu Ani beli tomat	Mrs. Ani buys some tomatoes
Tomat dibeli untuk soto babat	Tomatoes for making the soup....
Bagaimana kami mau sehat	How can we healthier
Kalau informasi HIV pun tidak kami dapat	If we don’t even obtain information about HIV
Bangun rumah bersekat-sekat	
Pantun kedua	Second verse
Pas istirahat minum jus alpukat	Build a house with lots of walls
Ayo gerakkan Pusat informasi kesehatan masyarakat	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 bimbang 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 lahiran
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, *Ibu*, come in.
Intan	*Ibu*, 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	*Bu* ……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, *bu*…
Midwife	I will prepare a referral letter to VCT in a hospital.
Intan	Yes, *bu*.

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 (*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 felt 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 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 accidently 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/mm^3 (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 population[78] 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).