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CLINICAL CARE **AND** SEXUAL AND REPRODUCTIVE HEALTH

of Women Living with HIV in Indonesia



Annisa Rahmatia

Clinical Care and Sexual and Reproductive Health of Women Living with HIV in Indonesia

Annisa Rahmalia

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The cover picture is a yoni—in Sanskrit means womb or reproductive organ—that became a sacred symbol of the female genitals in Ancient Javanese, combined with a reinterpretation of the red ribbon—the universal symbol of awareness and support for people living with HIV—and a red dot; together they depict yin and yang, the concept of complementary, interconnected, and interdependent opposite forces borrowed from Ancient Chinese philosophy.

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Table of Contents

Chapter 1	1
General Introduction and Outline of Thesis	
Chapter 2	13
Women with HIV in Indonesia – Are They Bridging a Concentrated Epidemic to the Wider Community?	
Chapter 3	33
“No Good Man Will Ever Want Me.” How Structural Social Inequality Increases Women’s Vulnerability to HIV Transmission: A Qualitative Study from Bandung, Indonesia	
Chapter 4	55
Are There Differences in HIV Retention in Care Between Female and Male Patients in Indonesia? A Multi-State Analysis of a Retrospective Cohort Study	
Chapter 5	87
Facilitators and Barriers to Status Disclosure and Partner Testing of Women Living with HIV in Indonesia: A Mixed Methods Study	
Chapter 6	111
“But My Husband Said: Who Will Take Care of Us When We Get Old?” A Qualitative Investigation of Childbearing Intentions and Reproductive Agency Among Women Living with HIV in Bandung, Indonesia	
Chapter 7	133
General Discussion, Conclusion, and Recommendations	
Appendix	151
Summary	153
Ringkasan	155
Samenvatting	157
Methodological, Professional, and Personal Reflexivity	159
Data Management	160
PhD Portfolio	161
Curriculum Vitae	163
Acknowledgements	165

Chapter 1

General Introduction and Outline of Thesis



HIV Epidemic in Indonesia

In Southeast Asia, unlike in Sub-Saharan Africa where the HIV epidemic is generalized and HIV prevalence is higher among females [2], it is mostly concentrated in certain population groups, with more males living with HIV [3]. In Indonesia—except Papua [4]—the main driver of HIV epidemic in the beginning was injecting drug use, a behavior more common among males [5]. The risk of sexual transmission to non-injectors [6,7] and the potential of transition to a self-sustaining heterosexual epidemic [8] were soon recognized. In 2018, Indonesia had a low HIV prevalence in the general population (0.4%) with high prevalence in certain key population such as female sex workers (FSWs) (5.3%), men who have sex with men (MSM) (25.8%), people who inject drugs (PWID) (28.8%), transgender people (24.8%), and prisoners (1%) [9]. The estimated number of people living with HIV (PLHIV) in Indonesia in 2018 is 640,000 (550,000 – 750,000) and women made up around a third of them (Figure 1.1).

There are an estimated 250,000 FSWs in Indonesia (**Figure 1.2**), and with an estimated HIV prevalence of 5.3% the estimated number of women living with HIV (WLWH) who were FSWs in 2016 is less than 15,000. The rest of WLWH are assumed to be sexual partners of male PWID and men who are clients of FSWs, although the latter is more difficult to identify as a population. The number of FSW population might be underestimated, because sex work is illegal in Indonesia and FSWs, particularly who worked independently, might be reluctant to be open about their occupation to a health worker due to fear of stigma and discrimination. Correctly identifying risk behavior of WLWH would be important in prevention of HIV transmission to children and sexual partners.

In Indonesia, prevention of mother-to-child transmission (PMTCT) coverage is low: only 15% (13% - 18%) of pregnant WLWH received treatment or prophylaxis to prevent vertical transmission [9]. In 2017, more than 3000 children were estimated to be infected with HIV and only around 10% of infection were averted due to PMTCT even though the proportion is growing over time (**Figure 1.3**).

The low coverage of HIV treatment is seen not only in pregnant women but across all PLHIV. Up until 2018 only 51% of the estimated number of PLHIV have been diagnosed and 17% were on treatment [9], far below the UNAIDS target of having 90% of PLHIV diagnosed and 81% (90% of those diagnosed) on treatment. The third target in the HIV treatment cascade, i.e. having 90% of those on treatment achieved viral suppression cannot be evaluated (**Figure 1.4**); access to viral load measurement among people on HIV treatment is scarce hence data on viral suppression is not available.

Adults (15+) living with HIV - by sex

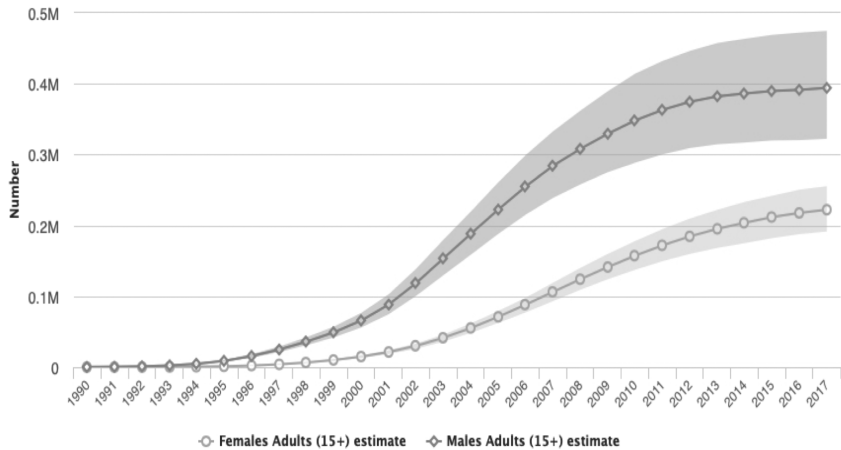


Figure 1.1 Estimates of adults (15+) living with HIV – by sex [10]

Sex workers: Population size estimates

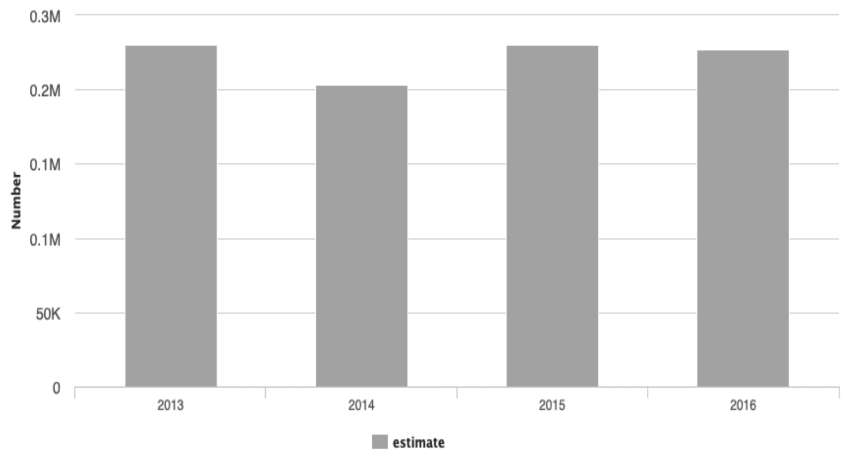


Figure 1.2 Size estimates of sex workers population [10]

Number of new HIV child infections vs number of new infections averted due to PMTCT

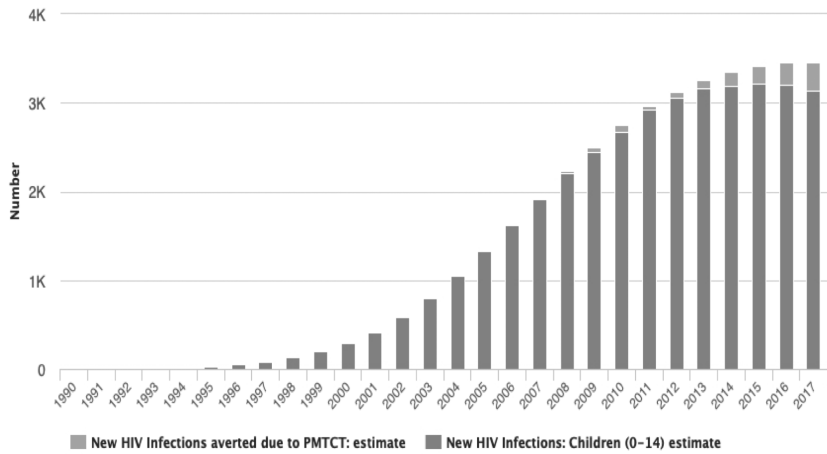


Figure 1.3 Estimated number of new HIV child infections vs new infections averted due to PMTCT [10]

HIV testing and treatment cascade (percent)

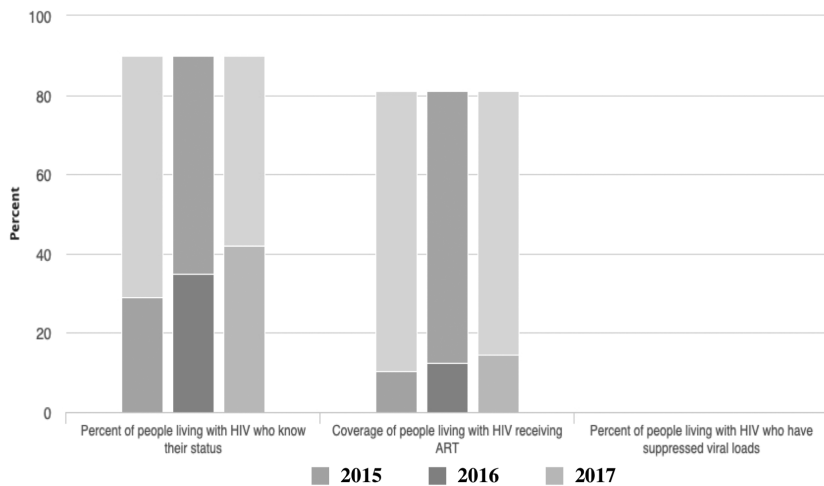


Figure 1.4 HIV testing and treatment cascade showing proportion of people living with HIV tested and treated among all people living with HIV in Indonesia [10]

The Context of HIV Positivity and Reproductive Health of Women in Indonesia

There are more men than women living with HIV in Indonesia. Although the number of infected women is fewer, their vulnerability is significant. Risk of HIV among women in Indonesia is almost entirely due to sexual transmission, which means prevention efforts should touch upon sexual and reproductive norms. These norms are related to heteronormative values around sex, relationships, and marriage. Sex and reproduction are expected only in marital relationship. In Indonesia, policies and regulations related to HIV evolved following international policies and consensus, but with certain changes to align with the cultural, religious, and social norms that are not defined in the policies but assumed to be understood in the same way by all actors involved [11]. The social and cultural constructions of gender lead to discrimination in health service [12], e.g. refusal to provide reproductive health services to unmarried women. Due to the religious tenets prescribing sexual life and the high coverage of male circumcision, HIV prevalence is hypothesized to be lower in sub-Saharan African countries with higher percentage Muslim population [13]. HIV prevention and treatment programs involving FSW and MSM, however, have been impossible to do in many Muslim majority countries across the world because of religious and cultural taboos against sex outside marriage, sex work, and homosexuality [14]. In Indonesia, traditional marriage practices (polygamy, early marriage, and contract marriage) could increase women's vulnerability to HIV [15].

The effects of social and cultural norms on health do not affect both genders equally. Indonesia ranks 104 out of 160 countries in gender inequality index (GII—a measure of gender-based inequalities in reproductive health, empowerment, and economic activity) [16] and 120 out of 168 countries in legal gender disparities [17]. Gender inequality often leaves women emotionally or financially dependent upon men and vulnerable in relationships [18]. In generalized HIV epidemic settings improvement in gender equality correlates with a decline of HIV prevalence [19]. Structural intervention is needed to improve gender equality [20].

Setting of the Research for this PhD

The research for this PhD was conducted in Bandung, the capital of West Java, Indonesia. Bandung was the main site for an HIV treatment and prevention project started in 2007 [21] that has led to evidence-based care and services for PLHIV. At

the beginning, the HIV research in Bandung was mainly focused on issues related to PWID [5,22–24]. Various aspects related to co-infection with tuberculosis [25,26], other co-infections [27–30], and HIV in prison setting [31–33] have also been studied. A study on risk behavior of people who no longer injecting drugs showed high risk of sexual transmission [34]. On HIV prevention, a school-based sexual and reproductive health education was developed for 8th grade (age 13-14 years) students in the city [35]. Networks with other centers in the country were built through multisite studies in young key populations (self-identified MSM, FSWs, and PWID aged 15-24 years) [36] and a multisite trial on test-and-treat among adult key populations [37]. Prior to this program, no studies had looked into the sexual and reproductive health of WLWH in this setting—also not among FSWs. In a similar setting in Jakarta many women were recorded getting HIV from their husband and identified themselves as housewives [38]. Recent research in other parts of the country has been done on HIV positive females who inject drugs [39] and those who were partners of PWID [40] but due to the assumed gender stereotyping, HIV cases in FSWs who had not been identified as such, and among other women without an obvious risk factor, might have been overlooked.

Outline of This Thesis

This thesis aims to get a better, in-depth, understanding about WLWH in Indonesia, particularly in relation to their sexual and reproductive health, in order to inform policy makers to help improve the lives and ensure fulfillment of reproductive rights of WLWH. Better prevention of HIV infection to and from women will contribute towards ending the epidemic. Using the HIV cascade of care to show the stages of events in the life of WLWH (**Figure 1.5**) and realizing that some understanding outside of the biomedical aspect is needed, despite not having trained in social sciences prior to the PhD I asked the questions in both the biomedical as well as social aspects related to WLWH: how do females compare to males in terms of characteristics and treatment outcomes, how and why were they exposed to and infected with HIV, and how do they live their sexual and reproductive life thereafter. To address these questions, I employed research methods in both epidemiology and social sciences. My research design falls within a pragmatist paradigm that arises out of actions, situations, and consequences with a concern with applications and solutions to problems [41]. I used a mixed methods approach of both quantitative and qualitative strands for complementarity and triangulation to answer the research questions.

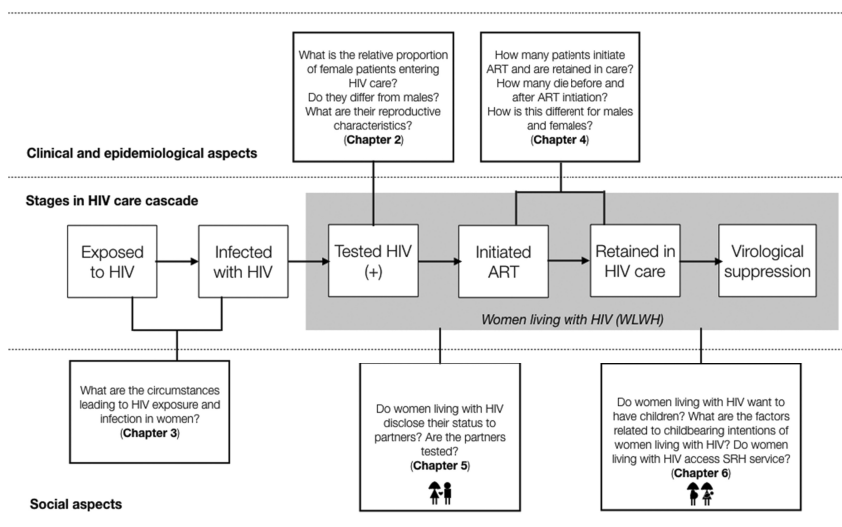


Figure 1.5 Overview of the questions addressed in this thesis in relation to HIV care cascade in Indonesia

In the initial stages of the HIV epidemic in Indonesia, injecting drug use was the main route of transmission. Since it is mainly men who inject drugs in Indonesia, HIV clinics had very few female patients. As sexual HIV transmission increased over time, more HIV-infected females were to be expected. In **chapter 2**, we examined if indeed more female patients presented over time at a provincial referral HIV clinic, how they differed from male patients, and what their reproductive history was. This was done in order to understand female patients' role in HIV transmission alongside the PWID population and their specific needs with regard to HIV care.

Due to the limitations in the data collection on patient characteristics, we obtained minimal information on HIV transmission risk behavior and potential transmission risk among female patients from routine data at HIV clinics. Presently, data are very limited in Indonesia regarding women's risk behavior and how this is affected by their sexual and reproductive agency.¹ We asked ourselves whether there are specific characteristics or circumstances leading to exposure and eventual HIV infection in a woman's life, and in **chapter 3** I present the results of a qualitative exploratory study beyond the HIV clinic, where data was collected from women living with HIV in the city of Bandung, Indonesia.

¹ Sexual and reproductive agency refers to women's capacity to make decisions in relation to their sexual and reproductive health in relation to the power structure and other social structures that influence their lives [1]

With a difference in clinical characteristics between female and male patients in Indonesia, there might be sex differences in HIV treatment cascade. In many parts of the world, gaps exist between the stages of HIV testing, access to treatment facility, initiating treatment, and retention in care, and in many settings some of these gaps are bigger for women. Using the cohort data in a referral clinic we examined if female patients were less likely than male patients to initiate treatment and/or remain in care (**chapter 4**).

In a concentrated epidemic setting like Indonesia, where HIV prevalence in the general population is below 1%, partners of PLHIV are sensible targets in HIV case finding. Status disclosure to sexual partners could be a key event in motivating partners to get tested. In **chapter 5**, we investigated if WLWH disclose their status to their sexual partners and whether they were tested, using a mixed qualitative and quantitative methods.

A woman's HIV serostatus has strong associations with her sexual and reproductive health. We asked the question if—in a setting with a concentrated HIV epidemic and a high expectation of women to have children like Indonesia—the reproductive intentions of a WLWH are influenced by her serostatus, and what are the other factors that might oppose or support these intentions. In **chapter 6**, I analyzed the results of the same qualitative study to investigate the childbearing intentions of WLWH in Indonesia, guided by the framework from the theory of planned behavior developed by Ajzen and Fishbein.

My thesis ends with a summary of the research findings and a general discussion (**chapter 7**).

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Chapter 2

Women with HIV in Indonesia – Are They Bridging a Concentrated Epidemic to the Wider Community?

BMC Res Notes. 2015;8:757

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Agnes R Indrati, Bacht Alisjahbana, Nel Roeleveld,
Andre J A M Van Der Ven, Marie Laga,
Reinout Van Crevel



Abstract

Background: Male injecting drug users drove the onset of the HIV epidemic in Indonesia but over time more women have been diagnosed. We examined the relative proportion of female patients in an HIV cohort and characterized their probable transmission route and reproductive profile.

Designs: Prospective cohort study in a referral hospital in West Java.

Methods: Interviews with standardized questionnaires, physical and laboratory examinations were done for 2622 individuals enrolled in HIV care between 2007-2012. The proportion of women in this cohort was compared with national estimates. The general characteristics of HIV-infected women and men as well as the sexual and reproductive health of HIV-infected women were described.

Results: The proportion of female patients enrolled in HIV care increased from 22.2% in 2007 to 38.3% in 2012, in line with national estimates. Women were younger than men, fewer reported a history of IDU (16.1% vs. 73.8%, $p<0.001$) and more were tested for HIV because of a positive partner (25.5% vs. 4.0%, $p<0.001$) The majority of women were in their reproductive age, had children, and were not using contraceptives at the time of enrolment.

Conclusion: HIV-infected women in Indonesia have specific characteristics that differ them from women in the general population. Further research to elucidate the characteristics of women exposed to HIV, their access to testing and care and sexual and reproductive needs can help reduce transmission to women and children in the context of concentrated HIV epidemic in Indonesia.

Key words: HIV, women, reproductive health, concentrated epidemic, Indonesia

Introduction

Indonesia has a relatively recent but rapidly growing HIV epidemic that, apart from the Papua provinces, is concentrated in some key populations. According to the Indonesia AIDS Commission the number of HIV-infected individuals increased at least three-fold between 2009 and 2014 [1]. An integrated biological and behavioural survey on key populations in 2011 found 41% HIV prevalence among people who inject drugs (PWID), 10% among direct female sex workers (FSW) and 8% among men who have sex with men (MSM) [2]; UNAIDS in 2012 estimated a lower prevalence among PWID (36.4%) and FSW (7%) and a similar estimate in MSM (8.5%) [3]. By 2014, the male-to-female ratio of cumulative AIDS cases in Indonesia was 1.8:1 [4].

Several studies have predicted the transition from a concentrated to a more generalized HIV epidemic due to the sexual behaviour of key populations [5–7], as has been observed in other settings [8]. In Indonesia, new HIV cases are projected to increase at a higher rate in men than women due to HIV incidence among MSM [9]. However, female partners of men who inject drugs [10] and MSM [6] may not be considered at risk for HIV and remain undiagnosed until they develop symptoms or lose a child due to HIV/AIDS. The delay in HIV detection in women poses a risk of not addressing the sexual and reproductive health (SRH) issues [11–13] important to prevent further transmission to children or other partner(s).

The prevention of mother-to-child transmission (PMTCT) program in Indonesia does not include HIV screening at antenatal care [14]. There is little information on seropositivity among pregnant women in the general population. Previous studies reported a 0% HIV cases among 2,450 pregnant women in Bali [15], 0.41% among 11,693 screened in eight cities between 2003 and 2010 [16] and 2.5% among 21,103 tested according to 2011 national report [1].

Investigating the transmission route of women infected with HIV and their risk of transmitting HIV to their children and/or sexual partners can help make epidemiological predictions and identify health needs of HIV-infected women in Indonesia. We therefore examined the ratio of men and women in a cohort of HIV patients [17] in a teaching hospital over a five-year period, and characterized the probable transmission route and reproductive profile of HIV-infected women in this cohort.

Methods

Setting and Study Population

The study was performed at Hasan Sadikin hospital, the main referral hospital in Bandung, the capital of West Java, a province of 43 million [18] in Indonesia, which has one of the highest HIV rates in Indonesia. Since August 2007 all subjects enrolled in HIV care have been included in a prospective cohort [19]. The Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University in Bandung, Indonesia approved the study, and all patients provided written informed consent. As one of the first 25 hospitals selected by the government to provide HIV care, this hospital has delivered free antiretroviral therapy (ART) since December 2004. CD4 testing became available in Hasan Sadikin hospital in September 2007 while measurement of HIV-RNA can be done since January 2008.

HIV testing was done through voluntary counselling and testing (VCT) or, when patients were referred from other departments within the hospital, through provider-initiated testing and counselling (PITC). HIV-infected patients were enrolled in care and given cART according to the national guidelines. Women who were found pregnant when entering HIV care were given prophylactic ARV and referred to the obstetrics department. HIV screening in antenatal clinics is no routine in West Java, including in the main referral hospital.

Clinical Procedures

Data on demographic factors and probable HIV transmission route were collected through interviews with standardized questionnaires. Questions about risk behaviour included inquiries about injecting drug use but not about commercial sex work—information about sex work was obtained only if patients mentioned ‘clients’ as one of their sexual partners. The attending physician examined patients to assess their clinical condition and possible co-morbidities but pregnancy tests were not routinely done.

Laboratory Procedures

Blood samples were taken for serological testing on HIV, hepatitis B virus (HBV), hepatitis C virus (HCV) and measurement of the CD4 cell-count per ml blood. HIV antibodies were measured using commercially available rapid tests (Determine HIV-1/

2, Abbott laboratories, Tokyo, Japan; SD HIV-1/2 3.0, Standard Diagnostic, Inc, Kyonggi-do, Korea); enzyme immunoassay (EIA; Virolisa, Index Union Diagnostic, Korea); and electrochemiluminescence immunoassay (ECLIA; HIV combi, Roche, Mannheim, Germany) in accordance with national guidelines. HBsAg, anti-HBs, anti-HBc and anti-HCV were measured by ECLIA (Roche diagnostic, Mannheim, Germany). External quality control of HIV, HBV and HCV serology (National Serology Reference Laboratory, Australia) showed 100% accuracy. CD4 cell measurements were taken using Facscount flow cytometry technology (BD Biosciences, Jakarta, Indonesia). External quality assurance for CD4 measurement was performed from COE Thailand and Qasi Canada ($SD < 1\%$).

Statistical Analyses

Each patient was assigned a code and all data were collected on standardized forms using the patient code and subsequently entered in a central database in Microsoft Access. A total of 2,833 individuals above 16 years of age—who were not recruited from the main narcotic prison of West Java [20]—had been recorded on March 31, 2013. This study analysed individuals enrolled in the HIV cohort between August 1, 2007 and December 31, 2012. Ten individuals (0.4%) who were already in HIV care before the cohort was started, 94 (3.3%) who entered the cohort after 2012, and 67 (2.4%) whose baseline variables were missing were excluded. Finally, 2,662 individuals, i.e. 1,781 (67%) men and 881 (33%) women were included for further analysis.

The proportion of women enrolled in HIV care in this hospital was compared with the relative proportion of women among new HIV cases according to national report from the Ministry of Health [21]. The general characteristics of HIV-infected women and men were compared using Chi-square for categorical values and Mann-Whitney-U tests for continuous values, and the sexual and reproductive health of HIV-infected women was described. The data are presented as line graphs, percentages or median (with interquartile range). Microsoft Excel for Mac 2011 (Microsoft Corporation, Redmond, WA) and Stata version 12 for Mac (Stata Corporation, College Station, TX) were used in the analyses.

Results

Trends in Women Enrolled in Care and National Epidemiologic Trends

Women made up an increasing proportion of the patients enrolled in HIV care in Hasan Sadikin hospital between 2007 and 2012, from 22.2% (24/108) in 2007 to 39.9% (129/323) in 2012 (**Figure 2.1A**). The laboratory of this hospital performed HIV tests for 1,624 (63.2%) individuals while the remainder were diagnosed elsewhere; 50.3% of them in other hospitals or testing facilities in Bandung, 30.6% in other cities in Indonesia, 1.9% in correctional facilities, 0.9% overseas, while for 16.2% this information was not available. HIV test were repeated for patients who could not provide written HIV test result from other testing facilities. Almost all patients came from the province of West Java and neighbouring Jakarta area—but the gender distribution was in line with national estimates of an increasing proportion of women from 34.4% in 2008 to 42.3% in 2013 (**Figure 2.1B**).

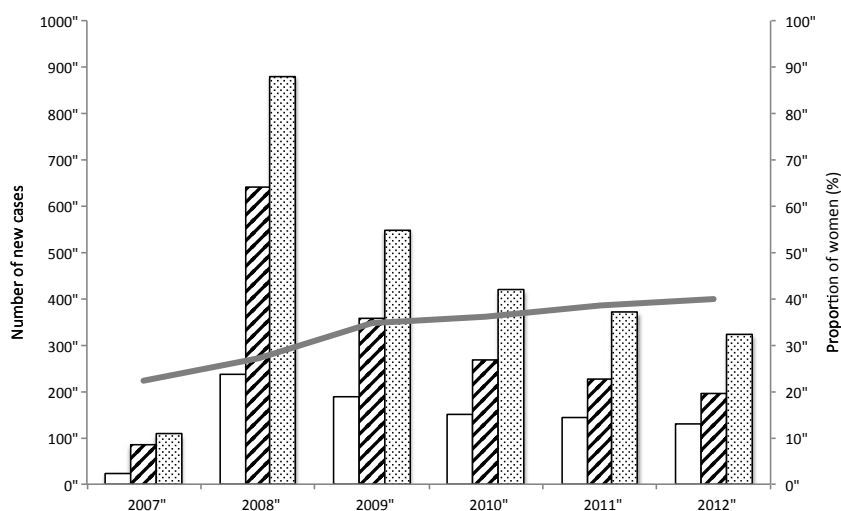


Figure 2.1A Proportion of female adult patients entering HIV care at Hasan Sadikin Hospital between 2007-2012

- ☐ Number of women
- ☒ Number of men
- ☒ Total number of new cases
- ☒ % of women

Left y-axis refers to bar graphs

Right y-axis refers to line graphs

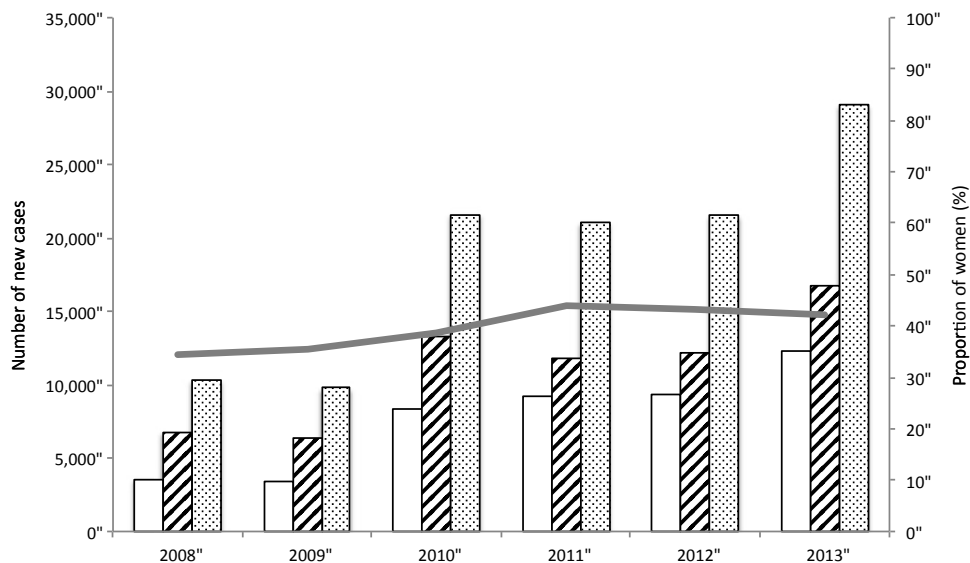


Figure 2.1B Proportion of female new HIV cases reported to the Ministry of Health between 2008-2013 [21]

- ☐ Number of women
- ☒ Number of men
- ☒ Total number of new cases
- ☒ % of women

Left y-axis refers to bar graphs
Right y-axis refers to line graphs

Characteristics of HIV-Infected Men and Women

Women in this cohort were younger, fewer of them had a job and more were divorced or widowed compared to men (**Table 2.1**). More women than men reported that their partners have had an HIV test (53.8% vs. 32.6%, $p<0.001$) and this was also true for the subgroup of married women and men (73.8% vs 64.6%, $p=0.001$). Men and women differed in their probable transmission route (**Table 2.1**): significantly fewer women than men (16.1% vs. 73.8%, $p<0.001$) reported a history of IDU, and more women had been involved in sex work (6.6% vs. 0%, $p<0.001$) and tested for HIV because of an HIV-positive partner (25.5% vs. 4.0%, $p<0.001$)—the two latter numbers were obtained from a subgroup analysis of 212 women and 348 men. Women also presented earlier with less advanced disease, fewer HCV co-infections and a higher CD4 cell count (median: 207 vs. 81 cells/ μ l; $p<0.0001$) (**Table 2.1**). Among the ART-naïve population, including 499 women and 904 men, CD4 cell counts were much higher in women compared to men (median: 176 vs. 41 cells/ μ l; $p<0.0001$). Fewer women than men had received ART prior to enrolment (18.1% vs. 28.4%, $p<0.001$). Seventeen women (2.4%) took ART as PMTCT, two of whom were pregnant when entering care.

Table 2.1 Baseline characteristics of HIV-infected men and women (n = 2662)

		Female* (n = 881)	Male* (n = 1781)
Sociodemographics			
Median age, years (IQR)		28 (25 – 32)	30 (28 – 34)
Education, n (%)	No education	2 (0.3)	2 (0.2)
	Up to 6 years	83 (11.3)	44 (2.9)
	>6 to 9 years	110 (14.9)	136 (9.0)
	>9 to 12 years	356 (48.3)	799 (53.1)
	>12 years	186 (25.2)	524 (34.8)
Occupation, n (%)	None	163 (22.1)	340 (22.5)
	Housewife	299 (40.5)	3 (0.2)
	Job in the past month	277 (37.5)	1166 (77.3)
Marital status, n (%)	Single	85 (11.6)	669 (44.5)
	Married	439 (59.7)	709 (47.1)
	Divorced/	211 (28.7)	126 (8.3)
	widowed		
Smoking, n (%)		188 (35.7)	776 (76.0)

Probable transmission route			
History of IDU, n (%)		112 (16.1)	1081 (73.8)
History of sex work, n (%)		14 (6.6)	0
HIV test because of partner notification, n (%)		54 (25.5)	14 (4.0)
Risk behaviour			
Condom use, n (%)	Never	337 (67.8)	427 (56.1)
	Rarely	33 (6.8)	48 (6.4)
	Sometimes	41 (8.3)	66 (8.8)
	Often	14 (2.8)	51 (6.6)
	Always	71 (14.3)	170 (22.1)
Clinical status			
WHO clinical stage, %	I	258 (39.6)	179 (13.5)
	II	58 (8.9)	83 (6.3)
	III	133 (20.4)	399 (30.1)
	IV	203 (31.1)	663 (50.1)
Laboratory parameters			
Median CD4, cells/ μ l (IQR)		207 (51 – 370)	81 (18 – 270)
Positive anti-HCV Antibody, n (%)		122 (22.8)	868 (74.9)
Positive Hepatitis B, n (%)		17 (2.9)	96 (7.7)
Reproductive health			
Pregnant, n (%)		43 (8.6)	N/A
Contraceptive use other than condom, n (%)		120 (22.5)	
Number of children, n (%)	0	179 (25.6)	
	1	320 (45.9)	
	2	142 (20.3)	
	≥ 3	57 (8.2)	

IQR = interquartile range; IDU = injecting drug use; HCV = hepatitis C virus

Data were missing for smoking (40.2% in women and 42.7% in men), pregnant (43.1% in women), condom use (43.6% in women and 56.8% in men), history of sex work (75.9% in women and 80.5% in men) and HIV test because partner is HIV positive (75.9% in women and 80.5% in men)

*Chi-square or Mann-Whitney tests p-value <0.01 for all variables presented

Sexual and Reproductive Health

More than half of the women (56.1%) never used condoms, less than a quarter of them reported other contraceptive use and some were pregnant at time of enrolment (**Table 2.1**). The majority of women had had a steady partner; only 11.6% were single while the rest were either married or divorced/widowed. Almost all women were in their reproductive age with one quarter of them aged between 16-25 years old and less than 1% older than 49.

The proportion of HIV-infected married women who had disclosed their HIV status to their husbands was higher than disclosure from men to their spouses (75.8% vs. 70.5%, $p=0.057$). Likewise, more women indicated that their husbands had been tested for HIV than men indicating their wives had been tested (73.8% vs. 64.6%, $p=0.001$).

Forty-three women (8.6%) were pregnant when entering HIV care (**Table 2.1**), but only one was referred to the HIV clinic from an antenatal service. A high proportion of women had at least one child (74.4%). There were no data of HIV status of these children; but 79 HIV positive children had been enrolled in the cohort with a median age of 3.1 years old and median CD4 cell count of 221 cells/ μ l.

Discussion

Our cohort shows an increase in the proportion of women among HIV-infected individuals between 2007 and 2013, in line with national estimates [21]. Compared to men, most women in our cohort were younger and presenting with less advanced disease. Fewer women reported a history of IDU or had HCV coinfection, showing a difference in HIV transmission route. Our findings also indicate that most women were or had been involved in a monogamous relationship: the majority were or had been married, had at least one child, and were not using contraceptives at the time of enrolment. A substantial proportion was pregnant, even though very few were referred from antenatal care.

The growing proportion of women in this cohort can have several explanations. Firstly, the project that started this HIV clinic had focused on IDU as the main transmission route of HIV infection in West Java in 2006 and targeted the PWID accordingly [17,22]. This project introduced counselling and testing among the female partners of male patient and as more partners were being tested, the number of women entering this cohort increased. Until 2013, HIV screening was not done in women attending

antenatal care in Indonesia [14] and HIV testing among sex workers largely relies on individual awareness [23,24]. Secondly, there might have been a real shift in the route of HIV transmission with IDU becoming less and sexual transmission becoming more important. Even among men, we observed a significant decrease of IDU as HIV transmission risk factor from 80% in 2008 to 30% in 2012 in this cohort. National report shows similar estimates: between 2007 and 2011, AIDS cases associated with IDU decreased from 50% to 19% and cases associated with heterosexual transmission increased from 42% to 71% [1]. A third factor contributing to a growing proportion of females in this cohort may be an underrepresentation of MSM at the Hasan Sadikin Hospital within the study period. Indeed national projections predict a considerable growth of male HIV patients from 2011 to 2016 due to homosexual transmission [9].

We characterized risk categories of HIV-infected women in this cohort. In contrast to male patients, few women were PWID based on self-report (16.1%) and confirmed HCV infection (22.8%) (**Table 2.1**). More than half of the women had a husband who had been HIV tested, but analysis of a subgroup of 212 women only identified 25.5% as female partners of HIV-infected men diagnosed through partner notification. The subgroup analysis also found 6.6% women involved in sex work. The number might be an underestimate because the question on sex work was embedded in the following: *"In the past month, whom did you have sex with? A) Long-term partner B) Casual partner C) Sex worker D) Client."* In South Africa, 21% of women attending routine antenatal care was involved in transactional sex associated with HIV seropositivity [25] and in Canada, a surveillance program established the risk categories for female HIV infection as 65% from heterosexual contact and 25% from IDU [26]. Clearly, sex work and other routes of HIV transmission need further study among HIV-infected women in Indonesia.

Almost all women in this cohort were in their reproductive age and sexually active. Compared to women of reproductive age with unknown HIV status in the 2012 general demographic and health survey (DHS), more women in this cohort were divorced or widowed (28.7% vs. 4.9%) [27]. High mortality among HIV-infected men in this cohort [28] most likely contributed to the high number of widowed women. A very high divorce rate among FSW (74%) [29] suggests that the relatively high proportion of widowed or divorced women in our cohort may also be due to undetected FSW. Few women remain without a partner for a long time in the aftermath of a husband's death, they remarry to protect their children's interests [30] and avoid the public stigma of being a divorcee or a widow [31]. A woman may not disclose her HIV status to an HIV-negative new partner [32], thus exposing him to a risk of transmission without proper prevention strategies.

Compared to men, women had less advanced disease, with higher CD4 cell counts and fewer complications, probably because women were mostly tested because of their husband's illness (**Table 1**). Testing of sexual partners of PWID is important in this setting; a cross-sectional study in a similar setting showed that this particular subgroup have a very high HIV risk [33]. Screening of women in antenatal care is not routinely done in Indonesia; indeed only one out of the 43 pregnant women in this cohort was referred from an obstetric care. This is in contrast to settings in sub-Saharan Africa where many women are diagnosed in antenatal screening as part of the prevention of mother-to-child transmission (PMTCT) program [34]. The Indonesian Ministry of Health Program Monitoring in Universal Access documented only 0.4% (21,103) out of 5,060,637 estimated pregnancies in Indonesia in 2011 tested for HIV [1]—and these tests were likely to be prompted by other risk characteristics identified instead of a screening in general population.

Our findings also raise the issue of family planning for HIV-infected women in Indonesia. Women in this cohort differ from women in general population surveyed in the DHS [27]: more were pregnant (8.6% vs. 4.3%) and fewer use contraceptives (22.5% vs. 44.4%) at the time of the cross-sectional data collection. This suggests that more women in this cohort were in a monogamous relationship at the time of enrolment, although it also highlights the need to focus on preconception and contraceptive care for HIV-infected women [35]. Younger women with no or one child generally desire more children [36] and in Indonesia, the social status associated with fertility [14] and religious values attributed to having children [37] may also influence childbearing desire. A lack of knowledge on mother-to-child transmission (MTCT) among HIV-infected women [38] increases the potential for vertical HIV transmission, but data on HIV in children to confirm this case is scarce. Indonesia adopted PMTCT as a national policy in 2005 [14] but by 2011 only 7.38% of women in need of PMTCT are getting the service [9] mainly in the form of prophylactic ARV, formula milk support and counselling.

This study was conducted in a single referral hospital, albeit serving around 35% of HIV-infected individuals in West Java [21]. Because it was not obtained from routine screening, the number of HIV infection in this cohort may not represent a true prevalence of HIV in the general female population hence data should be interpreted with caution. Commercial sex workers and MSM as key populations with high prevalence rates [39] may be underrepresented, limiting the generalizability of our findings. Moreover, some of the information relied on self-report, which may be

subject to a variety of biases including social desirability bias [40]. More than 40% of women have missing data on pregnancy status but there were no significant differences in age, education level, home address or marital status between those with missing or non-missing pregnancy status [41]. Finally, no information was available to identify couples of HIV-infected men and women, which might help establish transmission routes. The information gaps highlighted by this study may be used to guide further research.

Conclusion

The number of HIV-infected women in Indonesia is increasing and they might be bridging the HIV epidemic to a wider population in relation to their sexual and reproductive health. Further research to elucidate the characteristics of women exposed to HIV, their access to testing and care and sexual and reproductive needs can help prevent transmission to women and children in the context of the concentrated HIV epidemic in Indonesia.

Competing Interests

The authors declare no competing interests.

Authors' Contributions

AR is the main author of the manuscript and carried out the analysis. AvdV, ML and RvC provided scientific expertise and feedback throughout the development of the study and manuscript. HM contributed to the data analysis and helped draft the manuscript. RW and BA were involved in the study design, coordination and data collection. ARI carried out and coordinated the laboratory examinations. NR provided statistical support and edited the manuscript. All co-authors have seen and approved the final version of the paper and have agreed to its submission for publication.

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List of abbreviation

AEM	Asian Epidemic Model
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
cART	Combined antiretroviral therapy
DHS	Demographic and health survey
FSW	Female sex workers
HBV	Hepatitis B virus

HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
HIV-RNA	Human immunodeficiency virus-ribonucleic acid
IDU	Injecting drug use
MSM	Men who have sex with men
MTCT	Mother-to-child transmission of HIV
PITC	Provider-initiated testing and counselling
PMTCT	Prevention of mother-to-child transmission of HIV
PWID	People who inject drugs
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and testing

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Chapter 3

"No Good Man Will Ever Want Me." How Structural Social Inequality Increases Women's Vulnerability to HIV Transmission: A Qualitative Study from Bandung, Indonesia

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Abstract

Background: Understanding the pathways that expose women to HIV transmission are vital in improving HIV prevention, especially among a 'hidden' group of women without pre-established known risk for HIV.

Methods: We investigated the pathways which place certain women at greater risk for HIV in a qualitative exploratory study with theoretical sampling using an emergent theory study design in an urban setting in Indonesia.

Results: We conducted semi-structured interviews with 47 HIV-infected women, one focus group discussion with five young women who occasionally engage in sex work, participant observation at six sex work venues and two midwife clinics, and 11 informal interviews with midwives, nurses, and obstetricians. Our research found that many women not characterized as belonging to a 'high-risk group' or 'key population' were nevertheless at increased risk for HIV.

Conclusion: A history of sexual abuse, premarital sex, divorce, or involvement in sex work, often precipitated by poverty coupled with discriminatory public health policies further heightened women's exposure to HIV. While reaching at-risk populations is a key strategy in HIV prevention, a novel and more tailored approach is needed to reach more hidden categories of women with less apparent risk behavior yet considerable risk for HIV infection.

Keywords: HIV transmission; Indonesia; women; HIV vulnerability; gender norms

Introduction

The HIV epidemic in Indonesia was initially concentrated in key at-risk populations, particularly among people who inject drugs (PWID) (Afriandi et al., 2009). However, the epidemic was predicted to spread beyond the at-risk PWID population (Des Jarlais et al., 2012), and certain structural policies born from normative discrimination against sexual nonconformity in Indonesia have enabled this epidemic transition to other at-risk populations as well as to 'hidden' vulnerable groups (Indonesian Ministry of Health, 2014). With low HIV prevalence and incidence in the general population—0.4 and 0.3 per 1,000 population (UNAIDS, 2018)—identifying these vulnerable groups that are 'hidden' among general population is relevant to HIV prevention strategy. In a cohort of clients at the biggest HIV clinic in Bandung, Indonesia collected in over seven years, only 7% women identified as female sex workers (FSW), 16% women had a history of injecting drug use (compared to 74% of men), and 26% had a positive partner (4% in men) at HIV diagnosis (Rahmalia et al., 2015). Notably, more than 50% of these women could not be ascribed to a pre-established HIV risk group.

Social and structural factors can increase women's vulnerability to HIV acquisition, as seen in Nepal and Vietnam, where cultural sexual norms influence HIV vulnerability (Menger, Kaufman, Harman, Tsang, & Shrestha, 2015; Son et al., 2016). Identifying these new types of vulnerability is critical for further HIV prevention (Krishnaratne, Hensen, Cordes, Enstone, & Hargreaves, 2016). Therefore, we set out to understand what social factors increase women's vulnerability to HIV acquisition in Bandung in the midst of changing HIV epidemiology.

Given that socio-structural factors are multidimensional, accumulative, and difficult to assess (German & Latkin, 2012; Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008), we opted for a qualitative methodological approach to facilitate identifying the vulnerability pathways leading to HIV infection among Bandung women.

Methods

Study Site and Population

The study took place in Bandung, an urban area with 8.5 million population and 97% identified as Muslims (Statistics Indonesia, 2010, 2017). Bandung is the capital of West Java, a province with the third highest HIV incidence in Indonesia (Adriansyah & Firdausi, 2017). Employment in ≥ 15 year olds is 51% in women and 81% in men (BPS Kota Bandung, 2020).

Study Design and Sampling

Qualitative exploratory research was conducted to investigate the vulnerabilities and retroactive pathways to HIV among women living with HIV in Bandung triangulating in-depth open and semi-structured interviews and participant observation. Theoretical sampling was applied with a total of 52 women recruited for the study via telephone or face-to-face contact. For maximum sample variation, we recruited 47 HIV-positive women, including those who dropped out or had not started treatment, for in-depth interviewing from 3 HIV clinics, 2 public health centers, 4 sex work venues, 1 midwife clinic, 1 Red Cross blood donation center, and 1 tuberculosis clinic. We recruited five women for a focus group discussion who were 'indirect' sex workers (i.e. meeting online clients for sex while also having other jobs) and who tested HIV negative or have never tested to examine the dynamic of known risk with unknown HIV status. Finally, informal interviews were held with 4 obstetrician-gynecologists, 2 midwives, 1 general practitioner, and 5 nurses/HIV counselors to explore HIV testing and sexual and reproductive health (SRH) services.

Ethical Consideration

All in-depth interview participants provided written or verbal informed consent. The research received ethical approval from the Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University in Bandung, Indonesia No. 143/UN6.C1.3.2/KEPK/PN/2016.

Data Collection

In the *in-depth interviews*, data were collected with open-ended questions using a continuously adapted interview guide. A total of 47 interviews were carried out at public parks, cafes, or respondents' residence. For respondents whose male partners were involved in their HIV treatment, the partner was informed of study participation, but respondents chose whether partner could be present during interview. Only one respondent was interviewed with her husband present.

The *in-depth interviews* explored circumstances that potentially exposed women to HIV; sexual and marital history; and perceived power over decisions related to sex and healthcare. The lead author, native to the area and fluent in the local languages, conducted all interviews, allaying cultural and linguistic misinterpretation. Most interviews lasted between 1 and 2.5 hours. The interviews were not recorded, mitigating

any participant discomfort. The interviewer took notes during the interview, typed a full summary directly afterwards and made interview and analytical memos for each interview. The full summaries were written in English.

In the *focus group discussion* with five at risk women with unknown HIV status, we explored knowledge of HIV and their risk perception; risk behavior; and experience with HIV prevention and testing. All participants consented to audio recording prior to the interview. A co-author with experience in youth SRH programs facilitated the focus group discussion while the lead author transcribed the audio recording and translated it to English.

Participant observation was conducted during mobile VCT in 3 brothels, 2 massage parlors, and 1 karaoke bar. *Informal interviews* with 7 female workers at the sex work venues investigated their work situation, background, perceptions of HIV risk, and condom use. More *participant observation* and *informal interviews* with 2 midwives, 4 obstetrics-gynecologists, 5 nurses/HIV counselors, and 1 general practitioner working in sexual and reproductive health at public and private hospitals explored HIV testing and the scope of SRH services.

All data collected were stored in a password-protected folder and backed up to an external hard drive monthly. In the summaries, the researcher assigned pseudonyms unrelated to respondents' real name.

Data Analysis

The data were analyzed through inductive or open coding concurrent to data collection. The analyses were reiterated until data saturation. Axial coding was performed to facilitate the analytic process. Data management and analysis was carried out on RQDA in the *r* platform. Analytical validity was ensured by team approach to data analysis and coding, and by presenting initial findings to groups of colleagues and peers.

Concept Definitions

We define *vulnerability* beyond the common interpretation in epidemiology as risk, i.e. a probability of getting infected/becoming sick/having a condition with an increment of a risk factor. In this study vulnerability is related to perceptions, underlying social structures, and cultural logics rendering individuals susceptible to a disease by choice or by circumstance (Nichter, 2001).

HIV exposure refers to exposure via unprotected sexual transmission.

Sex work refers to all sexual activities where women received money or other material gains and perceived the activity as 'work.' It includes transactional sex between a mistress and her 'sugar daddy,' but not between a girlfriend and a boyfriend, nor a wife and her polygamous husband even though men in these relationships provide financial support.

Results

Based on our findings, we defined two categories of HIV transmission risk: women's risk (sex work; multiple marriages; multiple non-marital sexual partners; PWID) and their sexual partner's risk (PWID; had other female/male sexual partners). Theoretical saturation was reached upon completing semi-structured interviews with 47 women living with HIV, a focus group discussion with five young women engaging in occasional sex work and with unknown HIV status, participant observations and 11 informal interviews at sex work venues, public health centres, midwife clinics, and obstetrics and gynecology clinics at public and private hospitals.

Sample Characteristics and HIV Transmission Risk

All women living with HIV were between 18 and 42 years old, some with a rural upbringing, some having worked elsewhere in Indonesia. Ten women had dropped out of school at various levels. Six women had never been married nor had any children. Of the 15 women with a history of sex work, 10 were diagnosed during a screening at sex work venues (**Table 3.1**). Twelve women were diagnosed while pregnant: seven at antenatal care, three through a positive partner, and two based on symptoms. Six women had experienced sexual harassment or rape and 11 had experienced partner violence.

Table 3.1 Characteristics of HIV-positive women (n = 47)

Characteristics	Number
<i>Point of entry for HIV test</i>	
Partner sick or died of HIV-related illness	12
Child sick or died of HIV-related illness	3
Had symptoms of HIV-related illness	11

Antenatal care	7
Screening at sex work venue	10
Others (gynecology clinic, red cross, voluntary testing)	4
<i>Point of contact for interview</i>	
HIV outpatient clinic at provincial hospital	26
Municipal general hospital	5
Other HIV service providers	6
Community-based organizations	10
<i>Sexual debut</i>	
With boyfriend	17
With husband	23
Harassment	6
Selling of virginity	1
<i>History of partner violence</i>	
Experienced an abusive relationship	11

Given that HIV transmission risks can overlap, a Venn diagram was constructed (**Fig 3.1**). Partner's risk behaviors were discovered after HIV diagnosis through women's personal inquiries, or with the help of a counselor. Eight respondents chose not to inquire. The HIV transmission route could not be identified for four respondents.

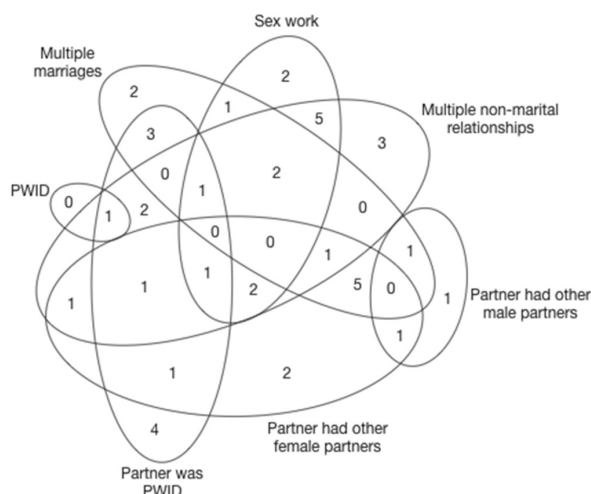


Figure 3.1 Venn diagram showing characteristics related to HIV transmission risk of the study participants. Possible HIV transmission risks were not identified in four participants

Pathways Leading to HIV Transmission

We found several plausible pathways leading to respondents' HIV exposure (**Fig 3.2**). Frequently precipitated by sexual abuse, premarital sex, or divorce, set to the backdrop of external systemic vulnerability, such as unequal gender norms, socioeconomic vulnerability, and discriminatory public health policies, respondents tended to be less discriminating in their subsequent sexual/romantic relationships, went on to have multiple marriages, multiple sexual partnerships, or engaged in sex work—leading to HIV exposure. These pathways all shared a common thread, namely (self) marginalization due to (in)voluntary nonconformity to social norms.

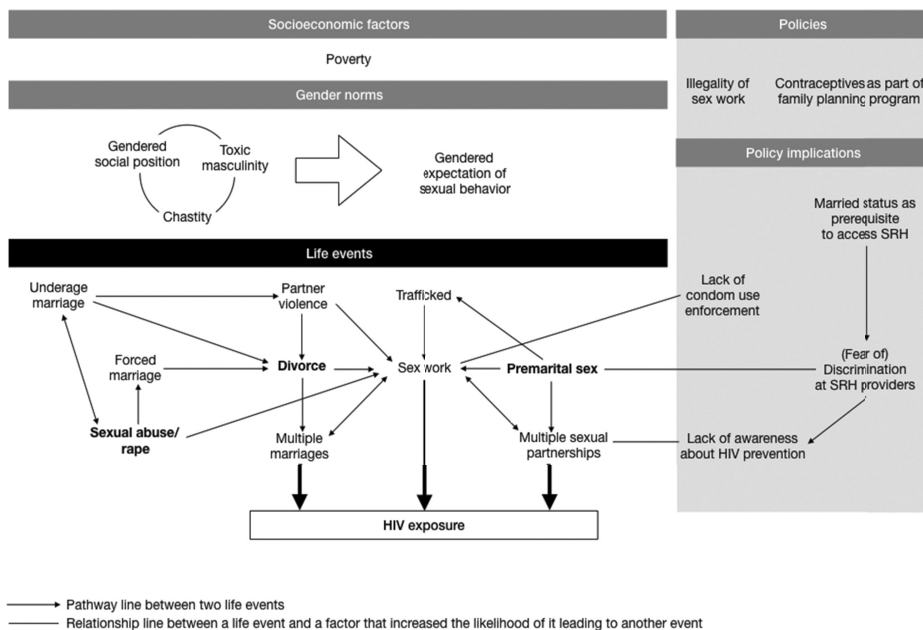


Figure 3.2 The pathways of life events leading up to HIV exposure (under the black box). Women have different events as starting point. Events written in bold are events that triggered the perception of low self-worth. The external factors (under the grey boxes) surrounding the life events are socioeconomic factors, gender norms, and government policies related to sex work and sexual and reproductive health.

Sexual Abuse

Six respondents cited suffering from sex abuse. One victim of childhood sexual abuse grew up believing in the taboo placed on her—a ruined woman.

“...I woke up to find my stepbrother on top of me, and I felt something wet... I was eight years old. I was too afraid to ask anyone, not even my mother. It happened several times... After that, I felt different. I felt sinful... When I got older, I felt like a broken person. I felt worthless. No good man will ever want me...” (Rukmini, 37)

Therefore, in adolescence she did not practice abstinence and dated a married man given that she had already lost her virginity. She later married a PWID. When they were both diagnosed with HIV, she expressed that she somehow merited it. Self-fulfilling prophecy of marginalization reinforces distance from conformity.

Premarital sex

Women whose first sexual experience was consensual premarital sex also accepted their HIV diagnosis as deserved. Seventeen respondents cited losing virginity to a boyfriend.

“...I had sex with a boyfriend back then... when I married my husband I felt lucky that he wanted me even though he knew I was not a virgin. So when he later told me he was HIV positive, I knew I had to accept him for he had accepted me [not being a virgin at marriage].” (Rininta, 38)

Divorce

Divorce was also stigmatizing and compelled many women to remarry whoever would take them, while simultaneously also breeding the perception that they were only worthy of a certain caliber of man. Eight respondents divorced and remarried before HIV diagnosis. Among divorced women, decisions to quickly remarry often meant only later discovering their new husband's extramarital sexual relationships and HIV risk. Believing she needed to remarry, but that she was only good enough for certain kinds of men, one woman chose to marry a divorced man over a bachelor only to find out that he had another wife after he had died of AIDS.

“...my boss set me up with his nephew. We went out several times, and he gave me a gold bracelet as a promise. I returned it when I met this man... I thought that was the right thing [to do]. The boss' nephew is a good

man, but he's a bachelor... He deserves a young unmarried woman... The other man was ten years older than me and he said he'd been married. So I thought we were more compatible. If I'd known then that he still had a wife I wouldn't have married him." (Maemunah, 38)

Multiple marriages

Five respondents had an arranged marriage for financial reasons. This set them on a cycle of divorces and remarriages that eventually exposed them to HIV.

"I got married three times. I was fifteen when I got married the first time. I am the oldest child and I have five younger siblings. My parents were poor... I was arranged to marry a distant relative soon after I graduated junior high school. I only met him once before marriage. I didn't want to get married then, but my parents had to marry me off because it helped with their finances." (Neni, 40)

Her first sex was forced by the husband, who was twice her age, and after a few months she ran away. She was diagnosed with HIV during pregnancy in her third marriage. Poverty entwined with domestic violence also forced women into increasing HIV risk.

"I did not finish school because I got married... He was around twenty at the time and I was fourteen. He asked my parents to marry me. We were poor so my parents said yes... But he hardly ever gave me any money... We moved a lot to find cheap rent... Once I caught him cheating, and he got enraged. He hit me and dragged me by my hair across the room. But he didn't want to divorce... so I left him and looked for work... One day this man offered to give me a ride... He was very nice. We became really close... He could give me up to 50k IDR [USD 3.50] per day. My husband has never done that. Even to get 10k IDR [USD 0.7] to buy food was very difficult. Sometimes I felt like a beggar asking him for money." (Tati, 39)

The man left her after she got pregnant and she could not contact him when she was tested positive for HIV in an antenatal testing.

Sex work

Marginalization and poverty also led to sex work. Some women were advised by close friends to pursue sex work after already having lost their virginity. Limited job opportunities—besides factory work—also fueled engaging in sex work. Ten respondents cited financial constraints as accelerants to sex work.

“...I started working [as a sex worker] to pay for my younger siblings’ education. My mother doesn’t work, and my father isn’t there... Me and my siblings have different fathers and none of them give my mother money... I would work until all my siblings finish high school. This kind of job should end with me.” (Esti, 21)

Marginalization after nonconformity to societal norms was often reinforced and perpetuated by family members, further setting into motion pathways to HIV exposure. Parents frequently forced their daughters to marry the first man they had had sex with—even in instances of rape.

“...Maybe I was drugged, because I hardly remember what happened... When I told my parents about [the rape], they were furious. My father went to look for him and urged him to marry me immediately. We got married a month later... Two days after the wedding, a woman with a baby came looking for my husband.... Apparently she was the first wife of my husband... I had no idea he has a wife... After that, sometimes he’d stay for a few days and then left, maybe to his first wife’s home, or maybe somewhere else... I didn’t want to ask for a divorce. I was already a ruined person, and being divorced wouldn’t be a good thing.” (Nina, 29)

Divorced women often faced significant pressure from parents, urging quick remarriage for social status.

Systemic elements

Institutional discrimination and structural inequality further heightened women’s vulnerability to HIV exposure; pregnant teenage girls were forced to leave school as cited by three respondents; and unmarried women were denied free contraceptives at SRH clinics as experienced by two respondents.

Sex work criminalization

Policies making sex work illegal bred underground brothels and illicit sex work activities at karaoke bars or massage parlors, complicating sexually transmitted infection (STI) prevention and screening programs. Five FSW respondents cited the challenges of asking clients to use condom in underground brothels.

Full quotes illustrating these findings are found in the Supplementary material table.

Discussion

This study shows that a complex interplay of factors affect women's vulnerability to HIV in Bandung, Indonesia. In particular, (in)voluntary deviations from social norms, such as suffering from sexual abuse, pre- and extramarital sex, divorce, or sex work, pave pathways to HIV infection among a hidden group of at-risk women. Social and structural inequalities, such as poverty, discriminatory policies for sex work, and unequal access to sexual and reproductive health programs further accelerate these pathways to HIV infection.

Sex work criminalization, condom confiscation by law enforcement, and sex work venue licensing (UNDP, 2012) has hampered STI prevention and increased transmission risk due to the lack of condom enforcement at sex work establishments (Basuki et al., 2002), workers operating outside of the system (UNDP, 2012), lack of risk perception among clients (Fauk et al., 2018), and the power imbalance in condom negotiation between clients and workers (Muchomba, Chan, & El-Bassel, 2015). However, outside of sex work, the systemic denial of access to contraceptives at SRH services for unmarried women (IPPF, 2016) is but one example of structural discrimination against a 'hidden' vulnerable group of women that exponentially increases their vulnerability to HIV exposure.

Stigma surrounding premarital sex has also facilitated HIV expansion. Though unmarried women are not expected to have sex, extramarital sex among youth is quite common (Irmawaty, 2013). Yet the lack of knowledge on safe sexual behavior due to poor sexual education may have diminished risk perception for HIV transmission (Wong, 2012) as most schools avoid sexual education altogether or only discuss biological aspects (Creagh, 2004; Pakasi & Kartikawati, 2013). A school-based sexual education program reaching over 81,000 teenagers in West Java (Pohan et al., 2011) was only permitted to promote abstinence (IMPACT, 2011) due to prevailing norms that youth sex is unhealthy or dangerous (Holzner & Oetomo, 2004). Moreover,

structural gender inequalities in sexual behavior stigmatizing women having engaged in premarital sex (Keleher & Franklin, 2008) may account for young unmarried women with sexual experience being more likely to resort to sex work (Miller et al., 2011).

Perception of nonconformity led to (self)marginalization that increased HIV exposure. An orthodox interpretation of religious tenets restricting the ways in which gender, sex, and reproductive matters are viewed in Indonesia (Bennett, 2005). While general HIV prevalence is lower in Muslim majority countries (Drain, Halperin, Hughes, Klausner, & Bailey, 2006), expectations of conformity to religious and social norms invokes guilt in women with (in)voluntary deviations. Involving religious leaders in HIV education (Kemper, Sihalohe, Siregar, Tromp, & Baltussen, 2016) should be implemented with caution; the use of language that judge certain behaviors could reinforce marginalization.

This study has several limitations. We strove for maximum variation in the process of purposive sampling, but some women and their vulnerabilities may have remained elusive. The retrospective nature of data collection signifies that the perceptions of certain life events reflects what respondents feel now versus when they happened. But as most were major life events, we believe that their significance remains accurate. To our knowledge, this is the first study investigating the intersect between characteristics of HIV-infected women in Indonesia and their vulnerabilities in the pathways to HIV exposure.

Though these 'hidden' at-risk women suffered from external social and structural marginalization, their acquiescence of and conformity to this marginalization further accelerated their pathways to HIV exposure. While reaching at-risk populations is a key strategy in HIV prevention, a novel and more tailored approach is needed to reach those with less apparent risk behaviour. Improving access to SRH education and services regardless of marital status and incorporating HIV testing in these services would contribute to HIV prevention among women in Indonesia.

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Appendix

Table A3.1 Quotes illustrating the structural social inequality that increases vulnerability to HIV transmission in women

Self-fulfilling prophecy and cycle of marginalization
<p><i>Due to sexual abuse</i></p> <p>"...I woke up to find my stepbrother on top of me, and I felt something wet. I was confused and not knowing what was happening. I was eight years old. But I was too afraid to ask anyone, not even my mother. It happened several times... After that, my mind often wandered. I felt different. I felt sinful. And I hate him... When I got older, I felt like a broken person. I felt worthless. No good man will ever want me..." (Rukmini, 37)</p> <p><i>After a divorce</i></p> <p>"...my boss tried to set me up with his nephew. We went out several times, and he gave me a gold bracelet as a promise. I returned it when I met this man on the train... I thought that was the right thing [to do]. The boss' nephew is a good man, but he's a bachelor and he's younger than me. So I was afraid he'd leave me for another woman someday. He deserves a young unmarried woman. The other man was around ten years older than me, and he said he'd also been married before. So I thought we were more compatible. But if I had known that he still had a wife then I wouldn't have married him." (Maemunah, 38)</p>
Lack of worth due to losing virginity
<p>"I dated one of the athletes, and I lost my virginity... I regretted it once it happened, and retracted from the relationship. But then it happened again several more times, with other boyfriends... My husband used to use drugs, but never injected. He knew I wasn't a virgin when we met, but he said not to worry, he's not a holy person himself." (Kania, 40)</p> <p>"...with my current boyfriend she didn't think it was a good idea either, because she said that as someone who's in the army, he's not going to be able to marry a non-virgin." (Asti, 22)</p> <p>"I have to admit I was not a virgin when we got married... when we got married I was lucky that he was a virgin. So when he told me later that he was HIV positive, I knew I had to accept him for he had accepted me for who I was when we got married." (Rininta, 38)</p>

Forced/arranged marriage

To a sex abuse perpetrator

"Maybe I was drugged, because I hardly remembered what happened. My parents were very upset when I told them [about the loss of virginity] and they urged me to marry this man immediately. So a month later we got married. I was eighteen. He was eleven years older than me... Two days after the wedding, a woman and a small child came by looking for him. She was furious. She said she's looking for her husband and a friend of his told her that she could find him there because he remarried. I had no idea that he has a wife... He often left the house for a few days, maybe to his first wife's home, or maybe somewhere else. I never really knew. I didn't ask for a divorce because I felt like I was already a ruined person, and being a widow won't be good for me." (Nina, 29)

"He was already a married grown man around my father's age... After that happened I didn't like it when this friend of my father's come over... I didn't even know I was pregnant until four months of pregnancy. I got married to this man, it was a nikah siri, we got divorced that same day. My parents helped took care of my baby." (Wati, 34)

Urged by parents after a divorce

"I didn't really know him before we got married. I was a single mother with one child, and I was working. I was always working. But my daughter, then two years old, got very close to this man who just moved to the neighborhood... One day my father told me: 'Stop fooling around. You are still young. You should remarry!' So I married this man. I didn't even know that he used to use drugs. It happened before we met." (Atikah, 42)

For financial reasons

"I was married once. It was an arranged marriage, when I just finished high school. I barely knew him before. My older sister was already working at the time, that was why I was the one married off. My mother wanted to relieve some of the financial burden, that, you know, since my father left." (Sari, 33)

"I was only thirteen at my first marriage, just out of elementary school. He was probably around eighteen, but I didn't know for sure. It was my uncle's idea, for economic reasons, you know... Since I was small my aunt and uncle raised me, while my twin brother was raised by our grandmother." (Masitoh, 28)

"...I was arranged to be married to my husband. He was somebody I met in the neighborhood. He was around twenty at the time, and I was fourteen. He asked my parents to marry me. We were poor so my parents said yes. So I didn't finish [junior high] school." (Tati, 39)

"I did not want to marry at the time, but my parents had to marry me off because it helped with their finances... I was fifteen and he was in his thirties... I did not want my husband to join me in bed for a long time... But then he forced himself on me when I was asleep." (Neni, 40)

Multiple marriages and poverty

"After finishing junior high school, I worked at a factory. When I was there I met this guy who became my first husband. He was from a very small and remote village. After marriage he asked me to move there with him. It is very very far from everything. To get to the village we have to walk five hours after getting off the public transport, passing through rice fields. I fell down in the rice field when I walked there while pregnant... I am moving back with my parents, taking our baby son with me. At first he came to visit us every month. But one day he stopped showing up... it turned out he was with another woman. So I divorced him... I moved to work at a billiard place... When I was there I met this guy who I married. He came to play with his friends... At first I did not know that he was a thug, that he didn't have any real job... When he was drunk sometimes he'd hit me. I also caught him cheating a few times. I wanted to divorce him but he did not want a divorce. So when I could not take it anymore I fled to my parents' house... my next husband was a sound technician at the karaoke." (Neneng, 32)

"I got married three times. I was fifteen when I got married for the first time. I am the oldest child and I have five younger siblings. My parents were poor... I was arranged to marry a distant relative soon after I graduated junior high school. I only met the man once before marriage. I did not want to marry at the time, but my parents had to marry me off because it helped with their finances." (Neni, 40)

Discrimination due to marital status/history

Accessing reproductive health service as a non-virgin unmarried woman

"...sometimes I got slurs from the staff when I visit an obgyn clinic, but I don't really care anymore. I always put my name as a 'Miss' and when they know what I went there for some would give me a side-eye. I just ignored it." (Febi, 28)

"I had used contraceptives when I was living with my boyfriend... We went to the midwife together and he told her we were married so she would not ask questions." (Asti, 22)

Due to being divorced

"His family didn't approve of him marrying me because of my marital status." (Neni, 40)

"We got close and he asked to marry me, but at the beginning I declined him. I was a widow with a baby, and he was single, surely he could find a better wife. But he said that, 'Even the prophet married widows.' He is an only son of seven children, and I'm sure her family would expect a better daughter-in-law. I was right. None of her family approved of me." (Ratih, 28)

Events that led to sex work

Rape/forced sex

"My sister did not like me working at a karaoke bar because she thought I was a virgin. I never told anyone but I wasn't a virgin at the time... I was raped when I was a teenager, maybe around the first year of high school. He was a family friend who lived in the neighborhood. He came to our house a lot, and had professed his interest in me. He said he wanted to marry me. But I didn't like him. He was much older than me. It happened at home, and it was not even empty at the time. He forced himself on me in the kitchen. I couldn't scream because he covered my mouth. It happened several times. I was afraid to tell anyone because I was afraid that I would have to marry him." (Marni, 25)

"...I was drunk but didn't lose consciousness. So I remembered when it happened. Somebody forced himself on me. After that I felt that I was already broken and I didn't care anymore. Then when I had a fight with my father I ran away with somebody I met to Padalarang... Somebody there brought me and another girl to Batam. But at first I didn't what kind of job I had to do. I was just told that I would be working. I was brought to a karaoke and was told that since then I worked there. I had to accompany guests to drink. When I tried to refuse the boss got angry... I was then introduced to this man who became my 'Abang.' He would give me money and I didn't have to work. So I never came back to the karaoke." (Mita, 24)

Losing virginity in a premarital sex

"My first sex was with a boyfriend in junior high school... I was afraid to tell my mother about it, but I confided in 'mamah', a family friend. She told me to come with her to Bandung, she could help me get a job. She told me that she's going to get me a job at a shop, but she took me to Saritem [name of a brothel area]. At first I was confused. But what else could I do? I didn't know anyone else there and I didn't know how to go home." (Esih, 28)

"After finishing junior high school I worked at a factory. I met someone there and I had my first sex with him. Then we broke up and I quit working at the factory. Somebody I know from my village brought me here [the brothel]." (Intan, 28)

"After finishing elementary school, I did some farming job and met a boyfriend through friends. We had sex, but then we broke up and he ended up marrying someone else... I wanted to go to Bandung to work, so I asked around. I didn't care what kind of job, any job will do. Then I met this guy who took me here [the brothel]." (Puspa, 31)

Partner violence

"...I told him to stop drinking once we got married. But it only lasted a short period of time. He hit me whenever he was drunk. He also brought girls home. Everytime I tried to leave he apologized and promised to change. But he changed for a while, then started drinking and hitting me again. I finally was able to flee, but I had to leave my children behind. Friends helped me to hide from him, but he once threaten my friend with a machete. I was on the run for a while until I found protection from the nice boss in Cimindi." (Maemunah, 38)

"After the divorce I got a job at a clothes shop. I didn't work there for a long time. Then I moved to work at a billiard place, and I met this man who became my second husband. He came to play with his friends. At first I didn't know that he was a thug, that he didn't have any real jobs. He stopped public transport to ask for money. He also liked to drink and used drugs. When he's drunk sometimes he'd hit me. I also caught him cheating a few times. I wanted to divorce him but he didn't want a divorce. So when I couldn't take it anymore I fled to my parents' house." (Neneng, 34)

"We split up before he passed away. I left him because of domestic violence. He hit me whenever he was angry." (Poppy, 32)

"Back then with my first husband we got divorce because of the family. He fought with my family; they did not get along well. He also got violent once and hit me. So we agreed to just get divorced." (Wida, 37)

"...he got angry. He hit me, pulled my hair, and dragged me on the floor. The neighbors saw what happened and reported him to the police. Then we got a divorce..." (Wati, 34)

"My second husband was also a farmer, like my mother. We got married around two months after we met. But he liked to hit me, not because he was drunk, just because he had a bad temper. Once he hit me when my cousin was in our village, after working in Bandung. She asked me to join her to work. She convinced me it would be better for me, I would escape being hit and earn money at the same time." (Dahlia, 23)

"During the marriage, me and my first husband lived with the in-laws. He sold toys at a school, but he did not go to work everyday. He often got drunk and was violent; at times he even dragged me on the floor..." (Masitoh, 28)

"...I love my mother even though she is not my real mother. Father, not so much. He liked to hit me. Now I'm being hit by my husband too. Sometimes when I wake him up because it was late and it was time to go busking, he would get angry and hit me." (Diah, 19)

"My ex-boyfriend liked to hit me when he got angry. He was also very jealous." (Asti, 22)

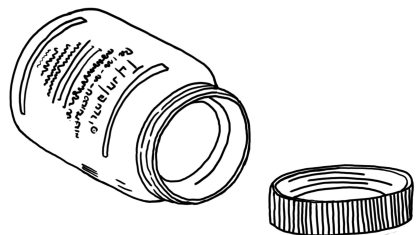
"I caught him cheating on me so I asked for a divorce. He got really mad and he hit me and dragged me by my hair across the room. And he didn't want to divorce me." (Tati, 39)

Chapter 4

Are There Differences in HIV Retention in Care Between Female and Male Patients in Indonesia? A Multi-State Analysis of a Retrospective Cohort Study

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Abstract

Background: Little is known about HIV treatment outcomes in Indonesia, which has one of the most rapidly growing HIV epidemics worldwide.

Methods: We examined possible differences in loss to follow-up (LTFU) and survival between HIV-infected females and males over a 7-year period in an HIV clinic in Bandung, West Java. Data imputation was performed on missing covariates and a multi-state Cox regression was used to investigate the effects of sex and other covariates on patient transitions among four states: (1) clinic enrollment with HIV, (2) initiation/continuation/re-initiation of antiretroviral therapy (ART), (3) LTFU, and (4) death.

Results: We followed 3215 patients (33% females), for a total of 8430 person-years. ART was used by 59% of patients at some point. One-year retention was 73% for females and 77% for males ($p = 0.06$). One-year survival was 98% for both females and males ($p = 0.15$). Females experienced a higher relative hazard to transition from HIV to LTFU (adjusted hazard ratio 1.21; 95% confidence interval 1.00–1.45), but this decreased after adjustments for clinical variables (aHR 0.94; 95% CI 0.79–1.11). Similarly, a lower relative hazard in females to transition from ART to death (aHR 0.59; 95% CI 0.35–0.99) decreased after adjustments for demographic variables.

Conclusion: This Indonesian cohort has low ART uptake and poor overall pre- and post-ART retention. Female-male differences in survival and retention were gone after adjusting for clinical and sociodemographic factors such as CD4 count and education level. Efforts should be made to improve retention among patients with lower education.

Introduction

Indonesia has one of the most rapidly growing HIV epidemics in Southeast Asia with an estimated 690,000 people living with HIV in 2015 [1], mainly in Jakarta, East Java, and West Java [2]. In contrast to the epidemic in sub-Saharan Africa where HIV prevalence rates are higher among women than men [3,4], the early stages of the HIV epidemic in Indonesia (outside Papua) mainly affected male drug injectors [5–7]. In subsequent years, HIV incidence increased among key populations such as men who have sex with men (MSM) and female partners of infected males [8] and improving all aspects of HIV care continuum for these populations is imperative [9]. Little is known about HIV treatment response and retention in care in Indonesia. Previous studies of HIV-infected individuals in Indonesia have focused on survival [10] in association with tuberculosis (TB) and cryptococcal co-infections [11,12], injecting drug use (IDU) [13], and imprisonment [14,15], but there are very limited data on retention in HIV care.

Retention in care, crucial for HIV treatment success [16], remains a major challenge globally. Both worldwide and in Asia about 50% of HIV-infected people received sustained ART in 2016 [17], while Indonesia has a much lower proportion of 14% in 2017 [18]. A recent study found only 76% of HIV-infected key populations who received ART in four cities in Indonesia retained in treatment [19]. In other settings, lower treatment retention has been associated with clinical determinants such as lower CD4 count and TB co-infections [20], health facility and structural-level determinants [21], and social determinants such as lack of a support group [22], IDU [23], imprisonment [24], younger age at ART initiation [25], and lack of occupation or education [26,27]. At the personal level, disease and associated perceived stigma, physical impairments, and general health-seeking behavior influenced retention in care [28].

Existing evidence on the difference of HIV survival and disease progression between males and females is inconsistent [29]. A poorer overall survival in males compared to females has been established in a systematic review and meta analysis of 31 studies [30], with correlations with older age and lower baseline CD4 [31,32]. Females experienced a higher incidence of adverse events [33,34] and treatment discontinuation [35–37], which might play a role in treatment retention. Various measures of lower socioeconomic status have been shown to correlate with poorer treatment outcomes [38,39], including lower pre-ART retention [40]. Studies have shown a lower socioeconomic status among HIV-infected females than males [4,41]. Indonesia experienced a growing proportion of female HIV patients who are usually

younger than males at time of diagnosis, with a higher chance of having experienced death of a partner or divorce [42].

Treatment retention can be studied by measuring LTFU, which in most observational studies is treated as a competing risk to survival [43]. Because retention is generally lower before than after ART initiation [44], we decided to investigate LTFU in both pre- and on-ART stages using multistate model [45]. This allowed stage-based effects in disease progression and treatment to be accounted for [46]. This model can be applied to the stages in the HIV care continuum from diagnosis, linkage to care, retention in care, receipt of ART, and viral suppression [47] and has been used to model longitudinal data with unobservable features [48], including in HIV chronicity [49]. Looking at the outcomes of each step in the HIV “care cascade” [50] can inform ‘Test and Treat’ and similar strategies to improve retention. In this study, we compared the rates of LTFU and mortality between females and males in a prospective cohort of HIV patients in Bandung, Indonesia.

Materials and Methods

Setting and Patients

The study population consisted of a cohort of HIV-infected individuals at an HIV outpatient clinic of a provincial referral hospital in Bandung, Indonesia between 2007 and 2014. Patients are enrolled in this clinic for one of two reasons: (1) a newly diagnosed HIV infection or (2) referral from elsewhere with an indication to start or continue ART. As per 2006 WHO recommendation, indication to start ART at the clinic was baseline CD4 <200 cells/mm³ or WHO clinical stage III or IV – the baseline CD4 limit was increased to <350 cells/mm³ in 2008. Choices of first-line ART offered in the national program are nevirapine (NVP), efavirenz (EFV), zidovudine (ZDV), stavudine (d4T – phased out in 2014), and lamivudine (3TC).

As per routine care, the clinic collects a set of baseline data at the time of enrollment that includes information on health status, HIV transmission risk behavior, and socioeconomic indicators. Regardless of ART status, regular follow-up interviews on risk behavior and reassessment of ART eligibility in patients not yet on ART are planned at 6-month intervals following baseline data collection. Patients receiving ART are expected to come every 30 days to collect their medication, unless they have a special agreement with the attending physician as explained below. Informed consent

for research was obtained from patients at the baseline interview and for patients under 18 years of age, with written assent from a parent/guardian.

This study only used routine data, and The Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University in Bandung, Indonesia approved the study. Patient inclusion criteria for this study were: age 15 years or older and non-missing value for date of first contact with clinic. We excluded patients recruited at the narcotics prison, because treatment follow-up for these patients depended on the prison and not the patient.

Data Collection and Analysis

Data for this analysis was extracted from the main clinic Microsoft Access database on October 3rd, 2014. Data was recoded and cleaned using Stata version 12 for Mac (Stata Corporation, College Station, TX, USA). Subsequently, reformatting and analysis was conducted in the R programming language [51]. Descriptive statistics for patient characteristics were compared between females and males using a chi-square test for categorical variables with two categories and a Kruskal-Wallis test for categorical variables with more than two categories.

Definition and Analysis of LTFU

Certain routine practices at the clinic complicate the definition and measurement of LTFU. During follow-up, the clinic does not record the date of the next clinic visit, nor does it actively send reminders to patients of their next appointment. Patients on ART receive medication for exactly 30 days at each visit, unless a special agreement for fewer or more days is made between the patient and the attending physician, in some cases up to 90 days. These arrangements are recorded in the patient record (on paper) and the pharmacy database, but not entered into the clinic's primary Microsoft Access database. Therefore, a delayed or missed visit for this analysis was estimated from the date of next visit. Tracking of patients with delayed or missed visits is conducted sporadically with phone calls or through outreach workers. Because 180 days of treatment interruption is associated with a higher probability of loss [52] we count patients who experienced such interruptions as LTFU despite possible reengagement into treatment beyond 180 days of interruption.

Multi-State Analysis

Fig 4.1 summarizes the multi-state model used in this analysis. All patients started in either the *HIV* state (i.e., clinical enrollment with HIV but not on ART) or directly in the ART state. From the *HIV* state, individuals can move to ART, *LTFU*, or *Death* states. *LTFU* and *Death* are absorbing states (i.e., final states). There are five possible transitions, each with a distinct hazard function that must be modeled. We used a competing hazards model since more than one transition can occur out of the *HIV* and ART states. Confirmation of death was obtained from family or community organization reports or by telephone calls conducted by the clinic [13]. Patients were censored at their end date provided in the clinic's Access database if their associated last state was 'Transferred' or if they had not reached an absorbing state at the administrative censoring date. For the multi-state analysis, we further censored patients who (a) had a final status that was neither 'Dead' nor 'Transferred' and (b) had a final status date less than 180 days before the administrative censoring date. The latter censoring was conducted in order to count the hazard ratio only of patients whose probability for LTFU was observable in the analysis based on our definition of LTFU.

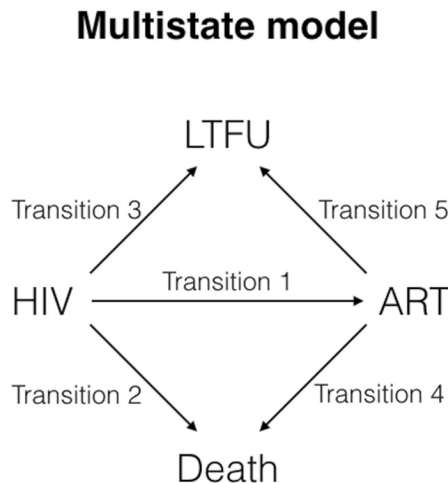


Fig 4.1 Multi-state model to assess LTFU.

State definitions: (1) *HIV state* – started at the earliest recorded date of contact with the clinic for HIV testing, HIV test confirmation, or baseline interview; (2) *ART state* – started on the recorded ART start date or—when this information is missing—the earliest date in the pharmacy record of medicine pick-up. Individuals who received ART on the day they entered the clinic were modeled as starting directly in the ART

state; (3) *Death state* – patients entered this state if their status is 'Dead' and the date of transition is the recorded date of death; (4) *LTFU state* – patients entered this state if the status is neither 'Dead' nor 'Transferred.' For patients who transitioned to LTFU from the HIV state, the date of LTFU is calculated as 90 days after the day the patient is expected to come back, i.e. 6 months or 183 days after the last recorded visit, so the date of LTFU is the date of the last recorded visit plus 273. For patients who transitioned to LTFU from the ART state, the date of LTFU is calculated as 60 days after the day the patient is expected to come back, i.e. 30 days after the last recorded visit (the LTFU date is the date of the last recorded visit plus 90 days); in cases where patients experienced multiple interruptions of 180 days or more, the date of LTFU is the date of the first interruption plus 90 days.

Cox Regression

We applied multiple Cox regression to adjust for sociodemographic and clinical variables that influenced treatment outcomes according to the literature [13,26,39,53–57]. All variables were made categorical. The sociodemographic variables considered were age (15–24; 25–39; 40–69), marital status at baseline (single; married; divorced/widowed/separated), home address (Bandung; Greater Bandung; other), education (non-completed basic = finishing only 6 years of schooling or no schooling; basic = finishing 9 years of schooling at elementary and junior secondary schools; secondary = 12 years of schooling up to high school; tertiary = any education beyond high school [58]), and occupation (any type of work; home maker or student; none). The clinical variables considered were ART prior to entry (yes; no), first recorded CD4 count (≥ 200 cells/mm³; <200 cells/mm³), Hepatitis C virus (HCV) co-infection (no; yes), TB treatment history (never had TB treatment; ongoing; past treatment – completed; past treatment – incomplete), anemia (no; yes). All the blood sample measurement results taken for this analysis were the earliest one on record. Anemia was included as a proxy measure for overall health [59]. We ran four different models: Model 1 included sex and age as covariates; Model 2 included all sociodemographic variables; Model 3 included sex and clinical variables; and Model 4 included all variables. Regressions were done after imputing missing data with multiple imputation using the R mice (Multivariate Imputation by Chained Equations) package [60]. In all four models we performed 1000 imputations with 20 iterations for each imputation and set the seed to provide reproducible results with a random number generated using www.random.org between 1 and 1,000,000.

Results

Between August 1, 2007 and October 3, 2014, 3811 HIV-diagnosed female and male patients were recorded in the database (**Fig 4.2**). The following groups were excluded from analysis: patients recruited at the narcotics prison (N = 291); those below 15 years of age (N = 164); those having incomplete information on key event dates (N = 67); and those who were tested for HIV but never had characteristics data collected (N = 26).

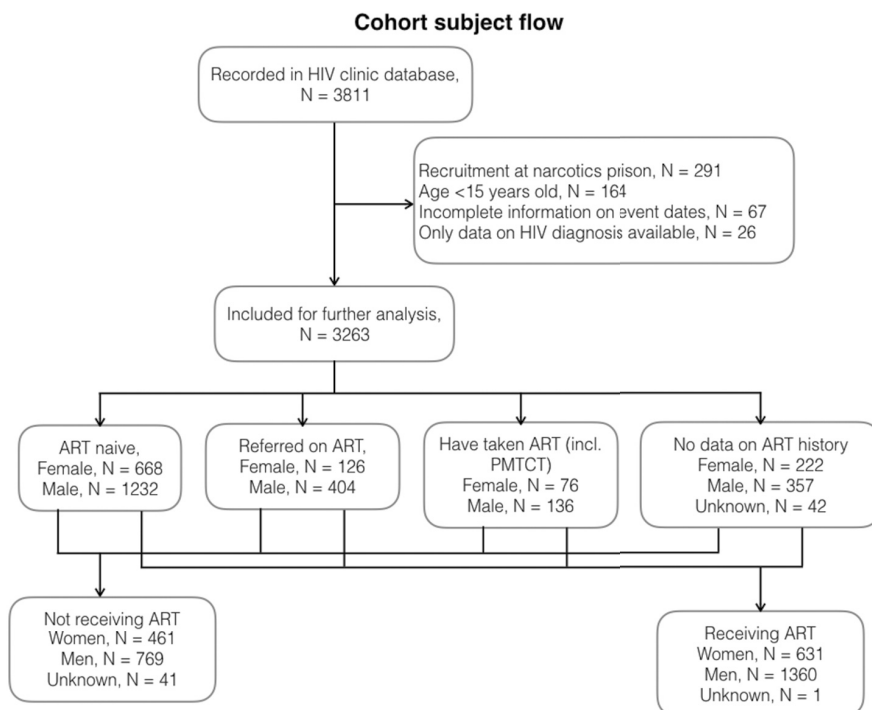


Fig 4.2 Subject flow.

Patient Characteristics

Among 3263 patients included, 1900 (58%) presented with newly diagnosed HIV infection, 530 (16%) were referred from other clinics for ART continuation, and 212 (6.5%) were referred with a history of prior ART at some point including for prevention of mother-to-child transmission (PMTCT). We further excluded 48 (1.5%) patients because their censored date was <180 days before the clinic administrative censoring date, and 51 (1.6%) patients because of missing sex data. We included the first CD4

count on record, which was taken within 90 days of first contact with the HIV clinic in 68% of patients who never received ART and was taken before or at ART start in 67% of patients who received ART. In 6% of patients receiving ART, the first recorded CD4 count was taken after ART start, while for the rest of the patients (12%) CD4 count data was not available. **Table 4.1** provides summary statistics of the study population, comparing 1069 females (34%) and 2095 males (66%). Females were slightly younger, more often widowed, divorced, or separated, and more likely to be unemployed. More males had received ART and fewer females had been treated for TB prior to entry. Fewer females had first CD4 count ≤ 200 cells/mm³ and hepatitis C co-infection. All differences were consistent when we only compared patients who received ART at the clinic, and all differences were statistically significant ($p < 0.05$).

Table 4.1 Summary of patient characteristics

	All patients N = 3215		Patients on ART at any time N = 1900	
	Female	Male	Female	Male
Number (%)	1069 (34%)	2095 (66%)	613 (32%)	1287 (68%)
Age category, N (%)	1035 (34%)	2033 (66%)	612 (32%)	1283 (68%)
15-24	25%	12%	25%	11%
25-39	69%	79%	70%	78%
40-69	6%	10%	5%	10%
Marital status, N (%)	904 (33%)	1804 (67%)	583 (32%)	1227 (68%)
Single	11%	45%	9%	44%
Married	62%	47%	63%	49%
Divorced / widowed / separated	27%	8%	28%	7%
Address, N (%)	936 (34%)	1855 (66%)	594 (32%)	1234 (68%)
Bandung	54%	61%	58%	64%
Greater Bandung	18%	16%	20%	16%
Other	28%	24%	22%	19%
Education, N (%)	887 (33%)	1778 (67%)	577 (32%)	1210 (68%)
Non-completed basic	12%	4%	8%	3%
Basic	16%	9%	13%	8%
Secondary	49%	53%	52%	52%
Tertiary	23%	34%	27%	37%

Occupation, N (%)	889 (33%)	1778 (67%)	577 (32%)	1210 (68%)
Any work	36%	76%	36%	77%
Housewife / student	43%	2%	44%	2%
No work	22%	22%	20%	20%
ART prior to entry, N (%)	854 (33%)	1750 (67%)	553 (32%)	1187 (68%)
Never had ART	77%	69%	72%	66%
Baseline CD4 level, N (%)	1069 (34%)	2095 (66%)	613 (32%)	1287 (68%)
CD4 <200 cells/mm ³	34%	46%	45%	53%
Hep C serology, N (%)	438 (31%)	962 (69%)	288 (31%)	641 (69%)
Anti-HCV positive	24%	76%	26%	78%
TB treatment history, N (%)	765 (33%)	1539 (67%)	496 (32%)	1036 (68%)
Never treated for TB	83%	72%	81%	69%
Ongoing treatment	10%	16%	12%	18%
Completed treatment	2%	3%	3%	3%
Incomplete treatment	4%	8%	4%	9%
Haemoglobin level, N (%)	780 (33%)	1554 (67%)	502 (32%)	1043 (68%)
Anemia*	52%	46%	53%	45%

Except for home address of patients on ART ($p = 0.01$) and anemia for all patients and patients on ART ($p = 0.003$), all p -values were <0.001 .

**Haemoglobin <13 g/dl for male and <12 g/dl for female [61]*

Treatment and Follow-Up

A total of 3215 patients were included in follow-up. ART was initiated in 1900 (59%) patients. Among 1868 ART-naïve patients, 608 (33%) never started ART, mostly because they either did not return ($n = 540$) or died ($n = 68$). Among 696 ART-experienced patients, 133 (19%) did not continue or re-initiate ART. The total follow-up amounted to 8430 person-years and total follow-up on-ART was 4632 person-years. Throughout the study period, 473 patients (15%) were transferred to another facility and thus censored.

Patient Survival and Loss to Follow-Up, Pre- and on ART

From a total of 3215 patients entered into the multi-state model, 2927 (91%) started in the HIV state while 288 (9%) received ART at entry and started in the ART state (**Fig 4.3**). Of all patients on ART ($n = 1900$), 177 patients (9%) had treatment interruption

episodes of 180 days or more (the longest interruption at 1507 days or more than four years); even though they eventually reengaged in care, these patients were treated as LTFU in this analysis. Pre-ART mortality was 4% and pre-ART LTFU was 30%, while in patients receiving ART, mortality was 6% and LTFU 38%. A total of 1059 (56%) patients on ART were retained at the end of the study period.

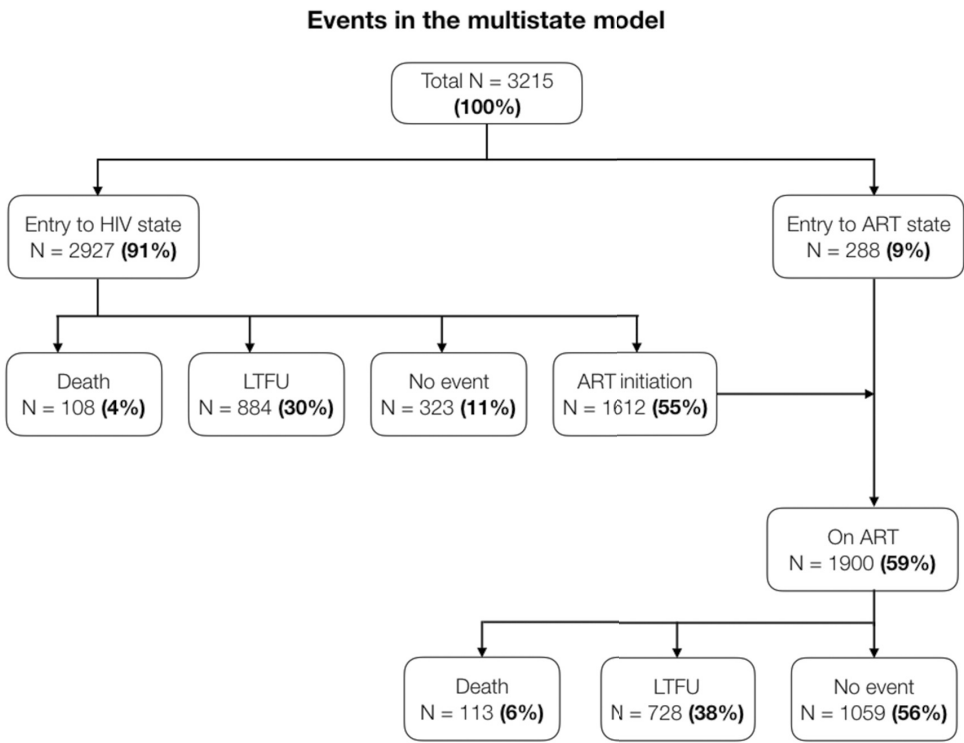


Fig 4.3 Events in the multi-state model.

Cox Regression

We applied Cox regression to adjust for the associations between sex and the five possible patient transitions between states; i.e., transition from HIV to ART, HIV to Death, HIV to LTFU, ART to Death, and ART to LTFU (**Table 4.2**). When adjusting for age, females had a significantly higher hazard ratio to transition from HIV to LTFU (aHR=1.21; 95%CI=1.05-1.39). When adjusting for clinical variables, females had a lower hazard ratio to transition from ART to Death (aHR=0.59; 95%CI=0.35-0.99) but this effect was

gone after also adjusting for demographic variables (aHR=1.03; 95%CI=0.89–1.21). We found no other significant difference between females and males in other transitions across all models. All outcomes from the models can be found in **S1 Table**.

Table 4.2 Association between sex and five transitions between states among HIV-infected individuals, giving hazard ratios (with 95% confidence intervals) across four models

	Model 1		Model 2		Model 3		Model 4	
	HR (95% CI)	p-val	HR (95% CI)	p-val	HR (95% CI)	p-val	HR (95% CI)	p-val
<i>Transition 1: HIV to ART</i>								
Male		1		1		1		1
Female	.90 (.81 – 1.00)	0.05	.92 (.80 – 1.06)	0.23	1 (.87 – 1.13)	0.94	1.03 (.89 – 1.21)	0.68
<i>Transition 2: HIV to Death</i>								
Male		1		1		1		1
Female	.86 (.56 – 1.31)	0.47	0.83 (0.46 – 1.49)	0.53	.75 (.45 – 1.23)	0.25	.95 (.48 – 1.87)	0.88
<i>Transition 3: HIV to LTFU</i>								
Male		1		1		1		1
Female	1.21 (1.05 – 1.39)	0.008	1.21 (1.00 – 1.45)	0.05	.94 (.79 – 1.11)	0.45	.99 (.80 – 1.21)	0.89
<i>Transition 4: ART to Death</i>								
Male		1		1		1		1
Female	.68 (.43 – 1.07)	0.10	.68 (.37 – 1.24)	0.20	.59 (.35 – .99)	0.05	.67 (.35 – 1.26)	0.22
<i>Transition 5: ART to LTFU</i>								
Male		1		1		1		1
Female	1.08 (.92 – 1.26)	0.35	1.07 (.87 – 1.32)	0.52	.95 (.79 – 1.15)	0.61	.97 (.77 – 1.22)	0.80

Model 1: adjusted for age

Model 2: adjusted for sociodemographic variables (age, marital status, address, education, and occupation)

Model 3: adjusted for clinical variables (ART history, baseline CD4 count, HCV co-infection, TB treatment history, and anemia)

Model 4: adjusted for sociodemographic and clinical variables

Covariate effects significant at <0.05 are shown in boldface

Discussion

There is little published data on HIV treatment outcomes in Indonesia. In this cohort of long term treatment in all HIV-infected patients we found low uptake of ART with many patients failing to start or restart ART and low retention in care (both before and after ART start). The retention and survival patterns were similar in females and males, with

females having slightly poorer retention and better survival. ART uptake, retention, and survival with and without ART were influenced by different sociodemographic and clinical variables.

One-year retention in care in this cohort (73% in females and 77% in males) was lower than in the Asia-Pacific region in 2016 (86%) [17]. Poorer pre-ART retention in this study correlated with being older, never having ART prior to entry to the clinic, and anemia. Male sex and lower education were identified as factors influencing pre-ART loss in Mozambique [62], whereas in this study the effect of sex and education diminished after adjusting for clinical variables. A study of HIV-infected key populations in four cities in Indonesia found being diagnosed at a facility that provided both testing and treatment services increased treatment initiation [19]. In this study, lower patient retention after receiving ART was associated with living outside the city and lower education. Analysis of Indonesian MSM and transgender subsample from an Asia Pacific AIDS Positive Network (APN+) study showed an improved retention in care among patients who started ART, had medical insurance, and used the Internet to find HIV-related information [63]. Other studies have associated lower treatment retention with lack of monthly income [64], lower education [54,65], and higher CD4 cell count [65,66]—characteristics that were more common in females than males in this study. Being older and having a higher education were correlated with ART initiation, while unemployed patients less likely to initiate ART. ART initiation was also associated with having a lower CD4 and ongoing treatment for TB. Similar to a study in Rwanda, ART initiation among patients with better clinical presentation seemed to be delayed [67].

Pre-ART survival was poorer for patients who were older, had lower CD4, and had anemia; on-ART survival was poorer for patients living outside the city and who had anemia (S1 Table). The correlation between unemployment and pre-ART survival diminished in the model that adjusted for clinical variables, suggesting a possible interaction between unemployment and poorer clinical presentation. Other studies have linked unemployment with long-term (more than 4 years) mortality during ART [68,69] in settings with higher retention than our cohort. When only adjusting for sex and clinical variables, males had lower on-ART survival, in line with other studies [54,70–72], but adjusting for sociodemographic variables removed this effect in our study. Lower survival, both pre- and on-ART, have also been associated with anemia in this population [73] and in a study in Puerto Rico [74]. Other studies also found an association between lower survival and tuberculosis co-infection [75,76], but we did not find significant associations between TB treatment history and survival in our results (Table 2).

The associations between state transitions and sociodemographic factors in this study are in line with other studies that found effects of low socioeconomic level [40] and migrant status [77] on treatment outcomes. In Europe, the association between education level and ART initiation reflects socioeconomic inequality [78]. Individuals with home addresses outside the city were less likely to receive ART and more likely to experience pre-ART loss. They are typically in the city temporarily for work. A study conducted at the same clinic found family support as a factor that increased retention [79], which migrant workers might lack.

This study has some limitations. We could not account for the probability of dying among LTFU patients due to lack of confirmation of patient deceased status. The effect of low CD4 on pre-ART LTFU supported the hypothesis that some of the patients categorized as LTFU might have died [80]. We included patients who were ART-naïve at entry and those with ART history prior to entry. It is plausible that some patients with ART history have been LTFU prior to entry and they entered this clinic due to symptoms, but our analysis could not account for this possible hidden heterogeneity. There is no standardized definition of LTFU; different definitions yield estimates that vary more than mortality estimates and that are less robust for long-term follow-up [81,82]. We used competing risk analysis to reduce bias of the competing risk of death in analyzing LTFU [83] in a multi-state model investigating each stage of transition [84], and Cox regression to test the multiple factors influencing them [85]. We could not measure treatment failure as an outcome of interest due to lack of CD4 cell plasma HIV-RNA monitoring during treatment [86]. According to the national guideline, patients receiving ART should have a 6-monthly CD4 count and annual HIV-RNA viral load measurements to evaluate treatment response, but while patients can get ART drugs for free, they have to pay for these tests, hence socioeconomic gaps between people with and without lab test data is plausible. We did not account for treatment interruptions, a relatively common occurrence among HIV patients [87] experienced by 97% of patients on ART in this population. Treatment interruption could correlate with treatment failure and retention in care [88,89]. In this cohort we had to censor 473 patients (15%) due to transfer because treatment data between facilities are not linked. Even though censoring transferred patients did not bias mortality estimates in another study [90], a better linkage between various testing and treatment facilities would reduce the need to censor transferred individuals and increase the accuracy of retention estimates [91,92]. We used education level, home address, and occupation—the covariates available in the database as measures of socioeconomic status—but some findings are difficult to interpret. A more in-depth study exploring the

relationship between treatment outcomes and socioeconomic status using specific variables would give a better picture [38]. Sex is only one aspect of gender issues influencing health systems but the nature of the study did not allow analysis of gender frameworks and gender power relations in HIV care in this setting [93]. Some baseline patient characteristics in this study have lots of missing data. Patients with missing data on baseline laboratory indicators (CD4 level, hemoglobin, and HCV co-infection) were more likely to not start ART and to be LTFU, and missing information on the history of tuberculosis treatment was significantly related to not starting ART. In this study we used information on TB treatment because information on actual TB diagnosis was not available; hence TB co-infection might be underestimated (an individual with no history of TB treatment may actually have TB). Despite the high occurrence of missing data, we used multiple imputations to yield correctly estimated standard errors and confidence intervals [94]. In our study we also present retention data beyond two-year follow-up, for which there is very little published data [95].

Conclusions

This study showed a poor pre- and post-ART retention and sex differences that could be explained by sociocultural and clinical characteristics of HIV-patients accessing HIV care and treatment in Indonesia. Efforts should be made to improve retention among patients with lower education levels. However, other aspects of HIV care continuum such as patient retention after treatment initiation remains a challenge. Further studies are needed to investigate the correlation between treatment interruption and treatment failure as well as factors influencing treatment reengagement after an interruption to give insights into ways to improve retention.

Competing Interests

The authors have no competing interests to declare.

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S1 Table. Cox regression results of the five state transitions (HIV to ART, HIV to Death, HIV to LTFU, ART to Death, and ART to LTFU)

Model 1: gender and age

Model 2: gender, age, and other sociodemographic variables

Model 3: gender and clinical variables

	Model 1		Model 2		Model 3	
	HR (95% CI)	p-val	HR (95% CI)	p-val	HR (95% CI)	p-val
<i>Transition 1: HIV to ART</i>						
Sociodemographic variables						
Sex						
Male	1		1		1	
Female	0.90 (0.81-1.00)	0.05	0.92 (0.80-1.06)	0.23	1 (.87-1.13)	0.94
Age						
15-24	1		1			
25-39	1.17 (1.02 - 1.34)	0.03	1.15 (1.00 - 1.25)	0.23		
40-69	1.49 (1.20 - 1.84)	<0.001	1.50 (1.20 - 1.87)	<0.001		
Marital status						
Divorced / widowed / separated			1			
Married			0.98 (0.89 - 1.24)	0.57		
Single			0.98 (0.82 - 1.18)	0.84		
Address						
Bandung			1			
Greater Bandung			1.10 (.95 - 1.27)	0.19		
Other			0.71 (.62 - .81)	<0.01		
Education						
Basic			1			
Non-completed basic			0.92 (.68 – 1.23)	0.57		
Secondary			1.22 (1.02 – 1.47)	0.03		
Tertiary			1.39 (1.14 – 1.69)	0.001		
Occupation						
Any			1			
Home/student			1.03 (.86 - 1.24)	0.73		
None			0.94 (0.82 - 1.08)	0.38		
Clinical variables						
ART prior to entry						
Yes					1	
No					1.14 (.99 – 1.30)	0.06

Baseline CD4

>= 200						1	
<200						1.89 (1.69 – 2.12)	<0.001

HCV co-infection

No						1	
Yes						1.05 (.91 - 1.22)	0.50

TB treatment history

Never						1	
Ongoing						1.21 (1.03 – 1.42)	0.02
Past-completed						0.87 (0.63 – 1.19)	0.37
Past-incomplete						1.03 (0.82 – 1.30)	0.78

Anemia*

No						1	
Yes						0.97 (0.86 – 1.09)	0.58

Transition 2: HIV to Deceased

Sociodemographic variables

Sex

Male		1		1		1	
Female	0.86 (0.56-1.31)	0.47	0.83 (0.46-1.49)	0.53	0.75 (0.45-1.23)	0.25	

Age

15-24		1		1			
25-39	2.64 (1.36 – 5.14)	0.004	2.59 (1.31 – 5.15)	0.006			
40-69	4.90 (2.05 – 11.7)	<0.001	5.10 (2.06 – 12.7)	<0.001			

Marital status

Divorced / widowed / separated				1			
Married			1.33 (.67 – 2.67)	0.42			
Single			1.07 (.50 – 2.28)	0.86			

Address

Bandung				1			
Greater Bandung			0.63 (0.31 - 1.30)	0.21			
Other			0.75 (0.45 - 1.25)	0.27			

Education

Basic				1			
Non-completed basic			0.34 (0.07 – 1.60)	0.17			
Secondary			0.78 (0.42 – 1.49)	0.46			
Tertiary			0.70 (0.34 – 1.45)	0.34			

Occupation

Any	1	
Home/student	1.23 (.52 – 2.88)	0.64
None	1.95 (1.20 – 3.13)	0.006

Clinical variables**ART prior to entry**

Yes	1	
No	1.38 (.75 – 2.53)	0.30

Baseline CD4

>= 200	1	
<200	2.39 (1.45 – 3.92)	<0.001

HCV co-infection

No	1	
Yes	0.68 (0.41 – 1.15)	0.15

TB treatment history

Never	1	
Ongoing	1.63 (0.92 – 2.88)	0.09
Past-completed	1.63 (0.60 – 4.42)	0.33
Past-incomplete	1.05 (0.35 – 3.14)	0.95

Anemia*

No	1	
Yes	2.12 (1.23 – 3.66)	0.007

*Transition 3: HIV to LTFU***Sociodemographic variables****Sex**

Male	1		1		1	
Female	1.21 (1.05 – 1.39)	0.008	1.21 (1.00 – 1.45)	0.05	0.94 (0.79 – 1.11)	0.45

Age

15-24	1		1	
25-39	1.44 (1.19 – 1.74)	<0.001	1.46 (1.20 – 1.78)	<0.001
40-69	1.96 (1.45 – 2.66)	<0.001	1.88 (1.37 – 2.59)	<0.001

Marital status

Divorced / widowed / separated	1	
Married	1.09 (0.87 – 1.36)	0.45
Single	1.04 (0.82 – 1.33)	0.74

Address

Bandung		1					
Greater Bandung		1.15 (0.93 - 1.41)		0.21			
Other		1.16 (0.99 - 1.37)		0.07			
Education							
Basic		1					
Non-completed basic		0.96 (0.71 – 1.30)		0.81			
Secondary		0.71 (0.58 - 0.89)		0.002			
Tertiary		0.74 (0.58 - 0.94)		0.02			
Occupation							
Any		1					
Home/student		0.89 (0.70 - 1.15)		0.39			
None		1.11 (0.93 - 1.33)		0.26			
Clinical variables							
ART prior to entry							
Yes				1			
No				2.08 (1.66 – 2.62)		<0.001	
Baseline CD4							
>= 200				1			
<200				0.67 (0.56 - 0.80)		<0.001	
HCV co-infection							
No				1			
Yes				0.91 (0.75 – 1.10)		0.32	
TB treatment history							
Never				1			
Ongoing				1.07 (0.81 – 1.42)		0.62	
Past-completed				1.03 (0.63 – 1.67)		0.92	
Past-incomplete				0.98 (0.68 – 1.42)		0.91	
Anemia*							
No				1			
Yes				1.26 (1.06 – 1.50)		0.01	

Transition 4: ART to Deceased

Sociodemographic variables

Sex

Male		1		1		1	
Female	0.68 (0.43 - 1.07)	0.10	0.68 (0.37 - 1.24)	0.20	0.59 (0.35 - 0.99)	0.05	

Age

15-24	1		1	
25-39	1.05 (.61 – 1.80)	0.87	1.10 (.63 – 1.90)	0.74
40-69	1.80 (0.83 – 3.91)	0.14	2.03 (0.91 – 4.54)	0.08

Marital status

Divorced / widowed / separated			1	
Married			0.94 (0.49 - 1.80)	0.86
Single			1.21 (0.61 - 2.44)	0.59

Address

Bandung			1	
Greater Bandung			1.86 (1.19 - 2.91)	0.006
Other			1.39 (0.83 – 2.32)	0.21

Education

Basic			1	
Non-completed basic			0.91 (0.29 – 2.81)	0.86
Secondary			0.81 (0.44 – 1.48)	0.49
Tertiary			0.57 (0.30 – 1.11)	0.10

Occupation

Any			1	
Home/student			1.04 (0.48 - 2.23)	0.93
None			1.56 (1.00 - 2.43)	0.05

Clinical variables**ART prior to entry**

Yes			1	
No			1.12 (0.68 – 1.83)	0.66

Baseline CD4

>= 200			1	
<200			1.58 (0.94 – 2.67)	0.08

HCV co-infection

No			1	
Yes			0.86 (0.53 – 1.40)	0.54

TB treatment history

Never			1	
Ongoing			0.95 (0.57 – 1.56)	0.82
Past-completed			1.01 (0.32 – 3.17)	0.99
Past-incomplete			0.53 (0.17 – 1.65)	0.28

Anemia*

No					1	
Yes				2.27 (1.41 – 3.65)		<0.001

Transition 5: ART to LTFU

Sociodemographic variables

Sex

Male	1		1		1	
Female	1.08 (0.92 – 1.26)	0.35	1.07 (0.87 – 1.32)	0.52	0.95 (0.79 – 1.15)	0.61

Age

15–24	1		1			
25–39	1.07 (0.87 – 1.32)	0.53	1.06 (0.85 – 1.31)	0.61		
40–69	1.25 (0.91 – 1.73)	0.17	1.20 (0.86 – 1.68)	0.27		

Marital status

Divorced / widowed / separated			1			
Married			0.81 (0.64 – 1.02)	0.07		
Single			0.98 (0.76 – 1.27)	0.88		

Address

Bandung			1			
Greater Bandung			0.90 (0.73 – 1.12)	0.34		
Other			1.38 (1.15 – 1.66)	<0.001		

Education

Basic			1			
Non-completed basic			1.91 (1.27 – 2.86)	0.002		
Secondary			1.21 (0.91 – 1.60)	0.20		
Tertiary			0.98 (0.72 – 1.32)	0.87		

Occupation

Any			1			
Home/student			0.94 (0.73 – 1.22)	0.66		
None			1.02 (0.84 – 1.24)	0.84		

Clinical variables

ART prior to entry

Yes					1	
No				0.87 (0.73 – 1.04)		0.13

Baseline CD4

>= 200					1	
<200				0.88 (0.75 – 1.04)		0.14

HCV co-infection		
No	1	
Yes	0.89 (0.72 – 1.09)	0.26
TB treatment history		
Never	1	
Ongoing	0.78 (0.62 - 0.99)	0.04
Past-completed	0.97 (0.61 – 1.55)	0.90
Past-incomplete	0.73 (0.53 – 1.00)	0.05
Anemia*		
No	1	
Yes	1.09 (0.91 – 1.30)	0.35

Covariate effects significant at <0.05 are shown in boldface.

*Haemoglobin <13 g/dl for male and <12 g/dl for female [61]

Chapter 5

Facilitators and Barriers to Status Disclosure and Partner Testing of Women Living with HIV in Indonesia: A Mixed Methods Study

Sexual and Reproductive Health Matters, *under review*

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Abstract

Background: This study examines HIV status disclosure and partner testing of women living with HIV (WLWH) in a concentrated epidemic setting.

Methods: We used a mixed methods study design to investigate status disclosure and partner testing of WLWH in Bandung, Indonesia. The qualitative exploratory strand used theoretical sampling to carry out semi-structured interviews with 47 HIV-infected women with varying ART status. The quantitative strand included 122 female patients receiving HIV care at a referral clinic.

Results: HIV diagnosis made women reassessed their sexual partnerships. Some women with a longstanding HIV infection formed new partnerships (35.2% in the survey). They disclosed their status to new partners without assistance from health providers; the type and stability of the partnership influenced decision to disclose. Fear of rejection prevented initial disclosure prior to bringing the new partners to a health provider for testing. Only 53.7% new partners of WLWH were tested (in contrast to 89.7% partners tested among WLWH who stayed with the same partner). In antenatal care, where testing often done on the same day for pregnant couples, more partners were tested. Consistent condom use was low in WLWH who formed new partnerships (24.3%) and who stayed with the same partner (30.8%). WLWH who continued sex work needed to shift to sex work settings where condom use was not enforced.

Conclusion: WLWH face barriers to HIV status disclosure and partner testing and would benefit from partnership counseling. Guidelines for partner notification and testing should include specific strategies for women with longstanding HIV infection.

Key words: HIV status disclosure; HIV partner testing; partner notification; long-term HIV; women living with HIV

Introduction

To increase the number of people tested for HIV, WHO issued a guideline on assisted partner notification services, involving tracing and offering HIV testing to partners of people living with HIV (PLWH) [1,2]. Health providers' assistance played a role in successful partner notification and testing [3]. Passive partner notification, i.e. when PLWH is expected to disclose their status to sexual partners without the active involvement of health providers, resulted in low number of partners tested [4]. Assisted partner notification services for people with newly diagnosed HIV has been implemented in many settings such as in sub-Saharan Africa and in other areas with concentrated epidemics [5–8]. Outside of sub-Saharan Africa, HIV transmission is more heterogeneous with around 80% of new HIV cases concentrated in specific at-risk populations and their sexual partners, making partner testing a strategic approach in HIV case finding and prevention [9].

In the era before combination antiretroviral therapy (ART) was widely available, an HIV diagnosis tend to lower the number of sex partners that an individual had [10]. As the widespread availability of ART increased life expectancy of PLWH, more PLWH with a longstanding infection resumed sexual activity in existing or new relationships, suggesting a potential need for partner testing in new sexual partnerships, even long after the initial HIV diagnosis [11]. Increasing new sexual partnerships, often combined with reduced preventive behavior, has been recorded in PLWH taking antiretroviral therapy (ART) for ≥ 4 years [12]. Status disclosure to new sexual partners can be challenging for PLWH with a longstanding infection [13]. Because partner testing is low without disclosure of HIV status of the PLWH, changes to health providers' counseling approaches are required to assist in status disclosure [11,14].

In Indonesia, the first wave of HIV epidemics spread mainly from men who inject drugs. Their (mostly female) sexual partners were expected to be the start of next phase of the epidemics [15,16]. A cohort study at the main referral clinic for HIV care found an increased proportion of new female patients in five years [17]. Among patients receiving care at HIV clinics, status disclosure to sexual partner less often happened among female than male patients; women living with HIV (WLWH) preferred to disclose their status to their mother or other family members [17,18].

Around the time when this study was conducted, there was no national protocol on partner notification and testing. However, the Directorate of Family Health of the

Ministry of Health was pushing for the development of a protocol for systematic partner notification services. Indonesian HIV protocols have been targeting key populations, but not all WLWH identified as such, including those who had been living with HIV for ≥ 4 years. To identify the needs in partner notification services in WLWH, we investigated the practices in HIV status disclosure and partner testing of WLWH in an urban setting in Bandung, Indonesia.

Methods

Study Site and Population

The study was conducted in Bandung, the capital of West Java, the province with the third highest incidence of HIV in Indonesia [19]. Bandung City Area is home to 2.5 million people with over 8.5 million living and working around the city [20]. It is a thriving, industrialized metropolitan area with a high income segregation and a growing urban slum [21]. Most inhabitants reported Sundanese as their ethnicity and Islam as their religion [22].

The first HIV testing and treatment service in Bandung was started in early 2000s at a clinic of the provincial referral hospital [23]. Voluntary counseling and testing (VCT) was available as an outreach program through community-based organizations working with people who inject drugs (PWID), female sex workers (FSW), and men having sex with men (MSM). VCT and additional harm reduction services were later expanded to selected public health centers at areas with known concentration of PWID in the community, after training one staff for HIV counseling. At the time of this study, antiretroviral therapy (ART) is provided at both the provincial referral hospital and the municipal general hospital, as well as several private hospitals and the abovementioned public health centers.

Despite the availability of services, a multi-site cohort study on key populations (PWID, FSW, and MSM) in Indonesian major cities, including Bandung, showed low treatment retention and viral suppression, suggesting an increased risk of transmission to additional sex partners and children [24].

Research Design

This mixed method study consisted of an exploratory qualitative strand combined with a second quantitative strand (commonly symbolized as QUAL+quan). In the exploratory study, we collected ethnographic data among WLWH in Bandung, Indonesia to understand their past vulnerability to HIV and their sexual and reproductive health in relation to HIV transmission [25]. This manuscript presents the findings related to sexual partnerships and partner disclosure of WLWH. Based on the qualitative data, we developed a questionnaire to collect quantitative data on the women's partnership status, HIV status disclosure to sexual partners, and the frequency of partner testing.

Concept Definitions

Women with longstanding HIV infection: To understand the factors driving sexual partnership of WLWH, we differentiate between newly diagnosed WLWH and women with longstanding HIV infection. In this study we define longstanding HIV infection as an HIV diagnosis ≥ 2 years before the study period, regardless of their HIV treatment status. The relevance of this distinction for this study lies in the basic assumption that although HIV acceptance and adaptation is a process with varying duration in different individuals, with time HIV diagnosis is increasingly accepted. In the literature, there is no convention on exactly how long since HIV diagnosis an individual is to be considered having a longstanding infection [26,27].

Sexual partnership: we defined sexual partnership as any heterosexual relationship involving sexual intercourse between WLWH and a man, that ranges from a husband to a sex work client.

Casual sex: we defined casual sex as a sexual intercourse between WLWH and a man who is not their main partner: it could be a sex work client, a boyfriend, or a non-committal sexual partner (a "fuck buddy").

Qualitative Strand

Data collection

Between February 2016 and April 2017, we carried out in-depth interviews with WLWH who had different types of partnership status and relationship history and conducted participant observation at sex work venues and midwife clinics that provided HIV testing. To complement the in-depth interviews, we had informal conversations with

sexual and reproductive health providers to understand actual behavior related to sexual and reproductive health services.

Sampling

We recruited WLWH from three different clinics providing HIV treatment, from an NGO providing mobile VCT at sex work venues (i.e. brothels, karaoke bars, and massage parlors), and from two private physician practices that care for HIV patients. At first we purposely selected women with different marital status (i.e. married, widowed, divorced, or single) and mode of HIV diagnosis (i.e. through having a positive partner, a positive child, symptoms, or antenatal care). Following the principles of gradual selection, we further recruited women who had not started treatment or dropped out of treatment. To ensure maximum variation, we later also included women who were diagnosed with HIV at sites that rarely found positive cases, such as tuberculosis clinics and a blood donation center. A more extensive explanation of the qualitative data collection and sampling methods has been published elsewhere [25].

Data analysis

The qualitative data was analyzed in a continuous, flexible, and iterative process, concurrent to data collection. Preliminary results helped us develop hypotheses and theories that were further tested in the field to confirm or refute the results through constant validity checks, until saturation was reached. Raw data was analyzed and coded to generate themes for further analysis. Data management and analysis were carried out in RQDA in R (R version 3.3.0, The R Foundation for Statistical Computing) and NVivo 12 Qualitative Data Analysis software (QSR International Pty Ltd. Cardigan, UK). The themes related to partnership, status disclosure, and partner testing were used to develop the questionnaire for the survey.

Quantitative Strand

Data collection

The questionnaire was based on the qualitative study results related to partnership, status disclosure, and partner testing. Additional questions related to sexual partnership were adapted from the UNAIDS questionnaire for sexual networks [28]. The first author administered the questionnaire in an interview that lasted around 30-45 minutes in a private room at the HIV clinic.

Sampling

During the time of study (i.e. the month of July 2018) 471 WLWH received ART from the clinic, with 352 of them (75%) visiting the clinic themselves, while the others had someone else pick it up (e.g. partner, outreach worker) for them. In a cohort study at the same clinic, 4% of male patients were tested following partner notification of female patients [17]. Assuming 4% is the prevalence of WLWH with male patients, with 95% confidence interval and $\pm 5\%$ margin of error, the sample size of WLWH with partners needed for this survey would be 60. Our qualitative data indicated that some women disclosed their HIV status to their partners, but the partners did not get tested; thus, we doubled the sample size in order to get a potentially representative sample of such women. The survey was conducted throughout the month of August 2018.

Data analysis

Questionnaire data was entered and cleaned in MS Excel and analyzed in R (R version 3.3.0, The R Foundation for Statistical Computing). Descriptive statistics and comparative analysis were computed to summarize the relationship between women's characteristics and partner notification and testing, contrasting between WLWH who stayed with the same partner after HIV diagnosis and those who formed new partnerships.

Ethical Considerations

The study protocol was approved by the Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University in Bandung, Indonesia No. 143/UN6.C1.3.2/KEPK/PN/2016. All participants received information before study participation about the objectives of the study, the topic and types of questions, and the intended use of results for scientific publications before participation. They were informed of the right to decline the interview or to withdraw any information during or after the interview. In the qualitative study, written or oral consent was given depending on the circumstances of the interview (formal interviews were documented with written consent, informal conversation relied on oral consent). Interviews were not recorded; the interviewer took notes during in-depth interviews and typed a full summary after the interviews. In the quantitative survey, the doctor at the HIV clinic explained the information about the objectives of the study, the topic and types of questions, and the intended use of results for scientific publications when patients came for their monthly follow-up at the HIV clinic. Then patients who agreed to participate were invited to another private room to be interviewed by the researcher.

Results

Study Participants

In the qualitative strand, data saturation was reached after in-depth interviews with 47 WLWH aged 18 to 42 years old. Fifteen of them had a history of sex work. The length of time they had lived with HIV varied from one month to over ten years. Their ART status varied: most were on ART, some had not initiated treatment, a few had dropped out or had not restarted ART after receiving it as part of PMTCT (before Indonesia adopted the universal lifelong ART for pregnant and breastfeeding women known as “Option B+” [29]). Those on ART were regular clients at one of three main ART facilities in the city. One WLWH was also interviewed in the quantitative strand.

In the quantitative strand, of 128 female clients approached for an interview, 122 agreed (response rate 95%). The median age was 35 (interquartile range [IQR] = 30–38.75). Their sociodemographic characteristics were similar to the qualitative study participants (Table 5.1). The women were regular clients at the HIV clinic, attending for their monthly or bimonthly ART. 68.9% (84/122) of them had been in care for at least 2 years and 68% (83/122) regarded their current sexual partnership as stable. Most stable partnerships were officially registered marriages, with fewer non-officially registered (religious or cultural) marriages or non-marital sexual partnerships.

Table 5.1 Characteristics of the quantitative study participants (N = 122)

Characteristics	Number	%
Age (in years), median (IQR)	35 (30 – 38.75)	NA
Education level		
Elementary	17	13.9
Secondary	71	58.2
Higher	34	27.9
Ethnicity		
Sundanese	94	77.0
Javanese	10	8.2
Others (Batak, Chinese, Malay, etc)	18	14.8
Birthplace		
Bandung city or surrounding towns	85	69.7
Another city in West Java	23	18.9
Another province in Indonesia	14	11.5
Duration of residence in the current city		
Since birth	46	37.7
>5 years	43	35.2

1-5 years	25	20.5
<1 years	8	6.6
Duration of ART at the HIV clinic		
≤2 years	36	29.5
>2 years (long term)	84	68.9
Have not initiated ART	2	1.6
Current marital status		
Married, officially registered	67	54.9
Married, not officially registered	8	6.6
Widowed, not remarried	12	9.8
Divorced/separated, not remarried	25	20.5
Non-marital partnership	8	6.6
Single, never married	5	4.1
Duration of current partnership (in years), median (IQR)	5 (2-8)	NA
Number of times married		
1	27	22.1
2	63	51.6
3	22	18.0
4	3	2.5

Sexual Partnership Post-HIV Diagnosis

Women saw HIV diagnosis as a major event affecting their sexual life. Those diagnosed because of a positive partner reassessed their relationship with the partner. This sometimes led to strained relationships and divorce or separation. WLWH who decided to stay with the positive partner reasoned that they “already carried his virus so there’s no point for leaving,” and they “would not be able to find another partner because of [their] HIV status.” Other reasons why women stayed in their relationships included love and compassion for their husband and a desire to take care of them; the determination to stick together “in bad times and good times;” the belief that this would benefit the children; and their perception that they had already had too many marriages or partners.

“...I still care for [my husband], despite everything... I feel pity for him, too... And I have to make this work for the children.... It’s also impossible for me to look for another partner now with this condition... When I lived separately from my husband for six months, it was difficult to find work on my own, while also taking care of the children.” (Marta, 32, WLWH who stayed with her positive husband)

WLWH who were diagnosed before their husbands had to consider status disclosure and, in cases where the husbands tested negative, the decision to stay married or not was primarily made by the husband.

Reasons for remarriage after a divorce or death of husband were avoiding rumors about their divorced/widowed status (not differentiated in Indonesian language), falling in love, or wanting better financial security. Many women who remarried, however, ended up in economic hardship, as their husbands did not make much money and they had other children (from previous marriages) to support.

“...my husband is just a day laborer at a farm, but I’m content [being married to him]. It is better to have a husband. [In the sewing business] I have many male employees, and as a widow when I acted friendly with them they thought I was teasing them. Now they don’t think so anymore because I’m a married woman.”
(Maemunah, 38, WLWH who remarried after her positive husband passed away)

Some female sex workers (FSWs) resumed sex work post-HIV diagnosis as they were still in debt to their pimp or due to the impossibility of finding new employment. Pimps and brothel management allow HIV-positive FSWs to keep working, unlike massage parlors and karaoke bars, where positive FSWs are immediately expelled. Consequently, some FSWs working in massage parlors and karaoke bars changed to work at brothels after testing positive.

After a divorce or death of their partner, some WLWH did not seek a new partnership as for fear of transmitting HIV and of being rejected due to their status. The fear was enhanced by other women’s experiences of being rejected. Another reason for choosing to remain single is past relationship trauma due to infidelity or violence. Women in this situation convinced themselves that taking care of their own health and their children was enough for their happiness.

In the quantitative survey, 32.8% (40/122) WLWH had been together with their current partner since before the HIV diagnosis, 35.2% (43/122) were in a partnership that was started after diagnosis, and 32.0% (39/122) did not have a partner. Only 97.5% (39/40) WLWH that continued in the same partnerships and 86.0% (37/43) WLWH in new partnerships were having sex with their partners in the past year.

Seven WLWH had had casual sex in the past year. Five of these women (three are married) had casual sex with one partner who they regarded as a boyfriend or “fuck buddy”. The other two were FSWs with multiple sex work clients. Few WLWH in the survey had not had any sex in the past year for reasons that corroborated our qualitative findings of WLWH who did not seek a new partnership. They only wanted sex in a marriage, were in a new relationship and needed more time before deciding

to have sex, or worried about partner's perceived ignorance of HIV transmission prevention and condom use.

Status Disclosure to Sexual Partners

In the qualitative study, we found women who were diagnosed as the wife of positive men. Their diagnosis was started with status disclosure, assisted by a health provider, and typically only when the husband was already severely ill or dying with AIDS.

In subsequent partnerships, most WLWH disclosed their status to a new partner without the assistance of a health provider; in fact, status disclosure was key to initiating partner testing, because it opened up the discussion about taking the partner to visit the HIV clinic to get more information and potentially get tested.

Women were careful in choosing when to disclose, but most of them did not consult anyone in making this decision. This resulted in delayed disclosure. Some women also believed that disclosing their status led their partner to cut communication with them.

"...I found out I was two months pregnant. I told him about [the pregnancy] and then we got a *nikah siri*¹*. ...[the doctor at the HIV clinic] said I should disclose [my HIV status] to my husband and bring him to the clinic... When our son was four months old I finally told him. After that he never visited me again and did not return my calls... I only received money occasionally through one of his employees and they would not give me his new number." (Wati, 35, WLWH who remarried after a divorce)

In other women, the fear of being rejected prevented them from disclosing their status, and it created a dilemma in relation to their childbearing wishes.

"We got married four months ago... I first met him as a client [at a massage parlor]. I have stopped working since we got married and moved back to [her hometown] while my husband works in Jakarta... he doesn't know my status and I don't know how to tell him... I wish we could have children, but I would have to tell him about this disease... So I don't know what to do..." (Intan, 31, WLWH who got married for the first time after HIV diagnosis)

¹*Marriage with only religious vows, officially unregistered, usually done if the bride or the groom is officially married to someone else

In the quantitative survey, 92.8% (77/83) women who were with a partner in the past year disclosed their HIV status. The proportion of disclosure is similar between women who stayed with the same partner or those who had a new partner after HIV diagnosis (94.9% vs. 92.7%, $p = 1$). WLWH who had had casual sex in the past year did not disclose their HIV status to any of the casual sex partners.

Condom Use with Sexual Partners

We also identified challenges in consistent condom use. Most WLWH said that their partners did not like using condoms, and FSWs could not enforce condom use to clients. To pressure her husband into using a condom, one woman deliberately avoiding other contraceptives, knowing that they both did not want more children. Condom use negotiation was also influenced by the type of relationship and HIV status disclosure. One woman's sexual partner took her insistence on using a condom as a sign of lack of trust in the relationship.

“...I wouldn't call him a boyfriend, now that I have this disease I'm afraid to have boyfriends. And I insisted that we use condom every time. He didn't like it, he thought I didn't trust him.” (Marni, 25, WLWH who had not disclosed her status to her new partner)

In the quantitative survey, we further compared duration of HIV care, risk profile (condom use, multiple partnership), HIV status disclosure, and partner testing between WLWH who stayed with the same partner ($N = 40$, 48.2%) and who had a new partner ($N = 43$, 51.8%) among WLWH who were with a partner in the past year (Table 5.2). Duration of care at the HIV clinic differed between the two groups (median and IQR of time since HIV diagnosis 3 (1-6) years vs. 6 (3-8) years, respectively, $p=0.002$). Consistent condom use was low in both groups (always used condom in the past year 30.8% vs. 24.3% respectively, $p = 0.46$). Among WLWH who had had casual sex, condom was used in the last sex with their sexual partner but FSWs frequently did not use it with clients.

Table 5.2 Comparison of characteristics, status disclosure, and partner testing between WLWH who stayed with the same partner and who had a new partner

Variable	Stayed with same partner (N = 40)	Had a new partner (N = 43)	P-value*
Age, median (IQR)	33.5 (29.75 – 39.25)	34.0 (30.5 – 38.0)	0.97
Time in care at HIV clinic (in years), median (IQR)	3 (1 – 6)	6 (3 – 8)	0.002
Have had sex with main partner in the past year	39 (97.5%)	37 (86.0%)	
Condom use with main partner (asked if they have had sex in the past year)			0.46
Always	12 (30.8%)	9 (24.3%)	
Often	10 (25.6%)	10 (27.0%)	
Half of the time	3 (7.7%)	0 (0.0%)	
Rarely	5 (12.8%)	8 (21.6%)	
Never	9 (23.1%)	10 (27.0%)	
Disclosure to partner	37 (94.9%)	38 (92.7%)	1
Partner HIV testing			<0.001
Partner was tested	35 (89.7%)	22 (53.7%)	
She does not know	3 (7.7%)	9 (22.0%)	
Partner refused testing	1 (2.6%)	10 (24.4%)	

*Wilcoxon rank-sum test for continuous variables, Fisher's exact test for categorical variables with cells containing <5 observations

Partner Testing and Treatment

Not all new partners of WLWH got HIV tested, even after status disclosure. The most common barrier to partner testing was the partner's reluctance due to thinking they might already contract HIV or they did not care if they were to get infected.

“...[my husband] never got tested. He doesn't want to. He knows about my status but he said he doesn't care if he gets it too.” (Bintang, 25, WLWH who got married for the first time after HIV diagnosis)

Most WLWH tested at antenatal care had their husbands tested. Testing on the same day ensured status disclosure and partner testing, and in the cases where the husband was HIV-negative, he accepted and was supportive of her HIV diagnosis. One woman

who did not have her husband tested on the same day nevertheless disclosed her status and made him accompanied her to the HIV clinic for ART initiation. He declined HIV testing at the clinic, saying he was not ready and would be tested later. He later told her that he went to a public health center and tested negative, but he never showed the results; thus, she suspected him to have lied to her about getting tested.

In the quantitative survey, 69.9% (58/83) of participants know the HIV status of their main sexual partners; 31.3% (26/83) had an HIV-positive partner. Among the positive partners, 18/26 received HIV care at the same clinic, 5/26 received care elsewhere, 1/26 was not in treatment, and two women were not sure about their partner's treatment status. 30.1% (25/83) WLWH do not know their partner's HIV status; 13.3% (11/83) said the partner had refused testing. More partners were tested among WLWH who stayed with the same partner than WLWH who formed new partnerships after HIV diagnosis (89.7% vs. 53.7% respectively, $p < 0.001$) (Table 2).

Role of Health Providers

The policy for partner notification and testing differed from clinic to clinic and evolved over time. Health workers at the main referral HIV clinic, where almost 50% of all HIV patients in the city received ART, believed they had no legal power to enforce partner testing of patients in a non-marital partnership, so they only targeted partners of patients in officially registered marriages. Until 2016, they had a penalty for new patients who did not bring their spouses for testing; these patients only received ART for two weeks instead of one month.

Partner notification by a health provider mostly occurred when a woman was tested with her partner present, such as at antenatal care or when she is sick at the hospital. In a few cases, the health provider notified the partner without the woman's consent.

"...the labor did not progress so they referred me to [a public hospital].... Then the doctor came and told me I was HIV-positive... He said I had to be referred to [a provincial referral hospital] for cesarean section and he asked who I wanted to disclose to... My aunt was there too and I preferred to tell her than to tell my husband... However, when we got to the [referral] hospital, another doctor asked my husband to sign [the consent form] before the surgery and told him my status..." (Mita, 24, WLWH who stayed with the same partner)

Women who started a new partnership post-HIV diagnosis had to disclose their status to the partner prior to taking him to an HIV clinic for further information and testing. In some cases, this led to inaccurate or incomplete information being shared with the partner about HIV transmission risk.

Discussion

This study found that while partner notification and testing has been emphasized for patients with newly diagnosed HIV, women with a longstanding HIV infection in Indonesia formed new partnerships and faced challenges in status disclosure to and testing of the new partner. Not all WLWH in Indonesia who were diagnosed as wives of positive men stayed with the husband. After a divorce or death of husband, some of them formed new partnerships. They faced challenges in initial status disclosure to new partners, prior to bringing them to a health provider for assistance with partner notification and testing. One of the main barriers to disclosure was the lack of stability in the sexual partnership. Furthermore, status disclosure did not guarantee partner testing or consistent condom use. WLWH who continued to do sex work had to deal with lack of enforcement of condom use at sex work venues and the lack of condom use awareness among clients. Some WLWH chose to remain single after a divorce or death of husband due to fear of rejection, fear of transmitting HIV, or past relationship traumas. These women convinced themselves that taking care of their children is enough for their happiness.

The findings presented in our study corroborated the evidence from previous studies. In other settings, the proportion of partner testing is higher among newly diagnosed HIV patients than among patients with longstanding infection; and the two groups face different barriers to partner notification [30,31]. Lack of interest in testing and the non-disclosure of HIV status were the main reasons for low uptake of HIV testing among partners of people with longstanding HIV in Thailand [32]. Partners can be difficult to contact, particularly in casual or transactional sexual partnerships [33]. Women in less stable types of partnerships and FSWs need a different approach to partner notification [34]. Only some WLWH in Indonesia had a history of sex work, however, as presented in this study they have many partners and intersecting social stigmas [25]. Most FSWs were victims of trafficking and sexual exploitation, and few were doing consensual adult sex work [35].

Due to recent evidence that HIV transmission risk is negligible from PLWH who adhere to ART and maintained viral suppression at an undetectable level, status disclosure might not be necessary for partner notification and testing [36]. However, status disclosure has benefits for the PLWH beyond the epidemiological benefits of transmission prevention. It increased social support, reduced depressive symptoms, and empowered WLWH with longstanding HIV [37–39]. Women are more likely than men to disclose their HIV status to a sexual partner for support [14]. Given good communication with health workers, counseling about sexual partnership could lead to status disclosure decision among WLWH [40]. Disclosure is easier when it is to family members than to the sexual partner and when it is (mainly among men) to a heterosexual partner than to a homosexual partner [41,42]. Perception of stigma, discrimination, and fear of abandonment hindered disclosure [38,41,43]. Status disclosure does not happen in sex work settings and FSW clients are among the most difficult population to reach, even though the HIV prevalence in this population is higher than the general population [44].

We found better partner testing coverage among women tested at antenatal care, where husbands were often tested on the same day. The success is likely due to couple testing, i.e. counseling and testing both the pregnant woman and her husband at the same time. Acceptance of couple testing is related to HIV risk awareness in both men and women and also to the availability of a supportive system [45,46]. Gendered socioeconomic barriers to couple testing were found in Malawi; men are often away from home for economic reasons and they fear exposure of their infidelity [47]. Formal invitation from the clinic is perceived to be more effective than a verbal request from a woman in making her partner come for couple testing in antenatal care [48,49].

This study has several limitations. With the focus on women we did not interview any male partners. A study in another concentrated epidemic setting found higher HIV prevalence among sexual partners of female patients than of male patients; thus, it would be reasonable to prioritize the sexual partners of female patients in partner notification strategies [50]. The lack of intervention during this study is a strength because the results reflect real life situation. Mixed methods study design allowed capturing WLWH with different treatment profiles and partnership typology; both factors can be relevant to partner notification approaches. To our knowledge, this is the first study in Indonesia that uses mixed methods to investigate partner notification and testing among women living with HIV.

Women with a longstanding HIV infection formed new partnerships and faced challenges in status disclosure to and testing of the new partner. The national guidelines for partner notification and testing should include specific strategies for these women. Partnership counseling could aide disclosure among WLWH who formed new partnerships. WLWH in unstable partnerships or sex work require a different approach than those who are legally married. Same day couple testing is effective at antenatal care and would improve coverage of overall HIV testing of pregnant women in Indonesia where coverage is low.

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No potential conflict of interest was reported by the author(s).

Data Availability

For the qualitative study, the datasets generated and/or analyzed are not publicly available due to the fact that the participants did not consent to have their full interview summaries made publicly available. However, the Nvivo database with excerpts of the summaries relevant to the study is available from the corresponding author on reasonable request. For the quantitative study, the datasets used and/or analyzed are available from the corresponding author on reasonable request.

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Chapter 6

"But My Husband Said: Who Will Take Care of Us When We Get Old?" A Qualitative Investigation of Childbearing Intentions and Reproductive Agency Among Women Living with HIV in Bandung, Indonesia

Reproductive Health, *submitted*

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Abstract

Introduction: Little is known about childbearing intentions and reproductive agency among women living with HIV (WLWH) in an urban setting with a concentrated HIV epidemic and traditional views of marriage and motherhood like Indonesia.

Methods: We conducted a qualitative exploratory study to explore childbearing intentions and reproductive agency of WLWH in Bandung, the capital of West Java. We used theoretical sampling with an emergent theory study design, and conducted semi-structured interviews with 47 WLWH and informal interviews with 11 health workers (midwives, nurses, and obstetricians). The Theory of Planned Behavior guided thematic analysis in childbearing intentions.

Results: In relation to their childbearing intentions, WLWH exercised agency in pregnancy, delivery, and contraceptive use. Some of their actions posed an increased risk of HIV transmission to their partner or children, e.g. non-disclosure of HIV transmission risk to husband in order to get pregnant or non-disclosure of HIV status to midwife to avoid having to deliver with Cesarean section. A woman concealed intrauterine device (IUD) insertion from her husband as a response to his childbearing expectations and her own fear of vertically transmit HIV. Behavioral and control beliefs played a bigger role than normative beliefs in influencing their intentions.

Conclusion: WLWH exercise reproductive agency in the face of personal and structural circumstances that support or oppose their childbearing intentions. Structural barriers hinder access to sexual and reproductive health (SRH) services that result in persisting fear of vertical transmission, unmet contraceptive needs and unplanned pregnancies, or prompt reproductive actions that increase risk of HIV transmission to their partner or child. Interventions at SRH service providers to reduce stigma and structural discrimination and to improve providers' understanding of reproductive agency are needed to ensure fulfillment of sexual and reproductive health and rights (SRHR) for WLWH.

Keywords: women living with HIV; childbearing intentions; reproductive agency; discrimination

Plain English Summary

We explored how women living with HIV decide to have or not have children and the ways they overcome the challenges to realize their decision. Our research shows that women living with HIV face restrictions in making open and informed decisions about having children, managing pregnancy, or using contraceptives. As women with HIV continue to face discrimination, they are fearful of their status being revealed to family, friends, or health workers. The fear prevents them from visiting health clinics or reporting their status to health workers. Consequently, many women living with HIV lack knowledge about preventing transmission or about involving their partner in managing their fears and expectations. Some women choose actions that increase HIV transmission risk to their children or partner. Healthcare services that are more friendly towards women living with HIV would be able to provide tailored assistance in order to promote informed and healthy decisions about having children, managing pregnancy, or using contraceptives.

Introduction

The importance of fulfilling the reproductive rights of women living with HIV (WLWH) has been recognized since before ART was widely available [1,2]. World Health Organization guideline on sexual and reproductive health and rights (SRHR) of WLWH urges health services to adopt the perspectives of women, their families, and communities [3]. Fulfilling SRHR for WLWH require strong evidence, government leadership, and civil society engagement [4,5]. Exercising reproductive rights is correlated with decision-making that implies individual agency. However, a woman's reproductive decisions are subject to external control, placing women's reproductive agency as an interaction between collective and individual agencies [6,7]. For women in many settings, constrained by gender norms and power imbalances, whether a reproductive decision was an agentic action is not apparent [8]. Restrictive gender norms and power imbalance are also observed at healthcare settings. The language used by health providers in discussing reproductive intentions influence women's reproductive agency and common stereotyping constitutes a barrier to agency [9,10]. Several factors have been suggested to influence women's reproductive agency. Decision-making ability is something that is nurtured in women's parental home [11]. Lack of knowledge, skewed information including from health providers, and societal expectations can undermine reproductive agency [12]. Women with unstable or no

income may be particularly vulnerable in having limited agency [13]. Higher level of education is associated with stronger reproductive agency even in cultural, social, and religious contexts that limit a woman's autonomy [14].

In Indonesia, the government supports societal control over women's reproduction. During the 32-year dictatorship of president Soeharto a woman's role as a wife and mother was made state ideology, and after the collapse of the dictatorship in 1998 it was replaced by a dominant narrative of conservative Islamism that still hailed the hegemony of family and married life [15]. Thus the norms that equate womanhood to motherhood and the practice of 'othering' women who do not become mothers are hardly contested [16]. Indonesian marital law restricts polygamous marriages and divorce but it allows a man to take another wife if his first wife cannot bear children [17]. Women's rights to sexual and reproductive health (SRH) services are based on substantive rights that only give access to married women [18]. Divorced and widowed women exercised agency to prove that they are good mothers in order to fight the stigma placed on their marital status [19]. Being outside of this patriarchal hegemony increased women's vulnerability to be infected with HIV, as observed in the higher level of divorce and widowed in WLWH in Indonesia [20,21]. In the presence of restrictive social practices and structures, the childbearing intentions of women living with HIV might not be reflected in their reproductive actions [22]. This qualitative study aimed at understanding reproductive agency in relation to childbearing intentions of WLWH in an urban area in West Java, Indonesia.

Methods

Study Site and Population

The study took place in Bandung, the fourth major city in Indonesia, home to over 8.5 million people, 97% of them are ethnic Sundanese and identified as Muslims [23]. Bandung is the capital of West Java, a province with the third highest HIV incidence in Indonesia [24]. Indonesia has a concentrated HIV epidemic with low prevalence in general population (except in Papua provinces) [25]. HIV prevalence is high in female sex workers (FSW) (5.3%), men who have sex with men (MSM) (25.8%), people who inject drugs (PWID) (28.8%), transgender (24.8%), and prisoners (2.6%) [26]. Many women in Indonesia became infected with HIV because they were subjected to structural social inequality and thus they could not be ascribed to a key population and remained "hidden" within the general population [20,21]. Our study population is WLWH in Bandung; some of them are part of the "hidden" population group.

Study Design, Sampling, and Data Collection

Details about study design, sampling, and data collection have been published elsewhere [20]. This study is focused on reproductive agency in relation to their childbearing intention. In a semi-structured in-depth interviews with women living with HIV, we retrospectively explored the reproductive events that happened after they were diagnosed with HIV, including pregnancy and delivery, contraceptive use, and experience with reproductive health providers; their perceived control or agency in their reproductive actions; and the beliefs and norms underlying their childbearing intentions.

Data Analysis

The data were analyzed through combined inductive and deductive approaches, with open coding conducted concurrent to data collection followed by thematic analysis with constructs that derived from the Theory of Planned Behavior (ie. attitudes, subjective norms, perceived behavioral control, and intention) [27]. The analyses were reiterated until data saturation was reached. RQDA in the r platform was used in data management and analysis. To ensure analytical validity, we employed team approach to data analysis and coding, and presented findings in several rounds to groups of colleagues and peers.

Concept Definitions

We decided to study reproductive *agency* to take into account that reproductive decisions are made within the social system that WLWH inhabit [28]. Within this study, *agency* is defined as the thoughts and actions taken by WLWH to maintain some control over their experiences and life trajectories [29]. *Reproductive agency* is defined according to Unnithan-Kumar as the ideas, actions, thinking, and planning in the domain of human reproduction by women and men who engage in reproductive activities and seek healthcare services [30].

Results

Based on our findings, we identified several actions or reproductive events in which women exercised agency in relation to their childbearing intention, namely getting pregnant, choosing to use contraceptives, and having vaginal delivery with deliberate

non-disclosure of HIV status to the health provider (Table 6.1). Theoretical saturation was reached upon completing semi-structured interviews with 47 women living with HIV and participant observations and 11 informal interviews at sex work venues, public health centers, midwife clinics, and obstetrics and gynecology clinics at public and private hospitals. The interviews with women living with HIV formed the basis of the main analysis for this study.

Table 6.1 Factors supporting reproductive agency of WLWH

Factors supporting reproductive agency in relation to childbearing intentions
<i>Getting pregnant</i> Not achieved desired number of children Believe children is future investment Assume womanhood and motherhood identity Partner's wishes to have children Children to strengthen marital bond Growing up without a sibling Knowledge of PMTCT
<i>Choosing to use contraceptives</i> Knowledge of different types of contraceptives Fear of transmitting HIV to partner/child Perceived inability to afford another child Fear of stigma due to non-breastfeeding
<i>Having vaginal delivery with deliberate non-disclosure of HIV status</i> Avoiding mandatory Caesarean section Avoiding stigma and discrimination due to HIV status

Sample Characteristics and Their Reproductive Situation at HIV Diagnosis

All women living with HIV were between 18 and 42 years old, with varying level of education from elementary to university level. Fifteen women were either a sex worker or had a history of sex work. Twenty-seven women were married at HIV diagnosis, ten were single, seven were divorced, two were widowed, and one was both divorced and widowed. Thirty one women already had one or more children when they were diagnosed and one had stepchildren. More than half of the women were diagnosed with HIV more than a year before interview.

Childbearing

Thirteen study participants who were not pregnant when diagnosed had one or more children after HIV diagnosis, nine of whom had also had children prior to diagnosis. For most of them childbearing was a natural life event instead of something they

actively decided upon after deliberation. Women expected children to take care of them when they grow old. Some women were taking care of their own aging parents and perceived it as an obligation and an honor. This obligation was perceived to only apply to biological children. Two women with stepchildren still wanted to get pregnant because they believed that stepchildren are not obliged to and would not take care of them. Non-childbearing was mostly expressed as circumstantial in relation to their lack of stable relationship/marriage (expressed by sixteen women), ill health (two women), or having achieved desired number of children (nine women). For some women achieving the desired number of children trumped their partner's expectation. A man marries a woman with children is expected to be financially responsible for all the children that the woman brings, so women who felt they had "too many" children said their new husband agreed on not having any children citing financial reasons.

One woman exercised agency in childbearing driven by a belief of the importance of children in marriage.

"...I got pregnant immediately after we got married... You know, the Javanese elders said that a couple needs a child to strengthen the marital bond, so I intended to have a child. Without a child, a man may leave you or cheat on you... I did not explain to him that HIV could be transmitted through sex so we did not use protection. After I got pregnant, I took him to the HIV clinic for testing and they explained it to him... [now] my husband never forgets to put [a condom] on." (Maemunah, 38)

Maemunah has her own business and earned more than her husband. She got married to escape the discrimination she faced as a divorcee and widow, and the *normative beliefs* that children strengthen marital bond and *behavioral belief* that her husband would not leave her if they have children led to her agency in getting herself pregnant. Some women expressed a mix of beliefs in support of and opposing their childbearing intentions. Partner's expectations to have children is also mentioned by other women in support of childbearing intentions, as well as other *normative beliefs* that they comply to such as societal expectations for a woman to bear children and religious understanding about procreation. Another *behavioral belief* that supports childbearing intention is that children would take care of them when they grow old. Few women perceived *control belief* that they could prevent HIV transmission to their children through the act of taking ART. Fear of transmitting HIV to their children is a *control belief* that tied to the *behavioral belief* that they should not have children so

that they would not risk transmitting HIV to their children, whereas societal norm of the importance of breastfeeding led to *the behavioral belief* that not having more children would avoid people asking them why they did not breastfeed.

Delivery

Twenty-two women gave an account of their delivery experience as WLWH. Twelve were diagnosed during pregnancy. All women but two were told they had to have Caesarean delivery. This became a cause of concern because of perceived pain, long recovery, and high cost. Four women stated they would not be able to afford Caesarean delivery and they had no access to government insurance. After two Caesarean deliveries prior to HIV diagnosis, one woman expressed a desire to experience vaginal delivery that she perceived to be an important experience as a mother. Most women complied with the required Caesarean delivery, but three women defied and looked for a different reproductive health provider who was unaware of their HIV status and they deliberately refrained from disclosing their status in order to avoid Caesarean delivery.

"...in my first pregnancy I went to a midwife not too far from home when I went into labor. I only disclosed my status after the baby was born. Then the midwife scolded me and told me to never returned. So I went to a different midwife to deliver my second child, and this time I did not disclose my status." (Bintang, 25)

Some personal beliefs support the intention to deliver with Caesarean section. *Normative beliefs* that they have to comply with medical recommendations motivated the intention. There is also a *behavioral belief* to want to deliver their baby with an obstetrician affiliated with the HIV clinic to avoid having to actively disclose their status again because it's already disclosed. Many women perceived *control belief* that the act of Caesarean delivery can prevent HIV transmission to their children. Intentions to avoid Cesarean section were driven by different beliefs, notably the *normative belief* about the importance of vaginal delivery experience in motherhood and *behavioral beliefs* that led them to think they could avoid the painful recovery of Caesarean delivery and avoid discrimination at obstetric care by not disclosing their HIV status.

Contraceptive Use

Family planning dialogue with health providers rarely happened and some women had unmet contraceptive needs. Seventeen women who did not want to get pregnant used condom, intrauterine device (IUD), or sterilization at the time of interview. But two women

were not aware of IUD insertion after childbirth. They considered to take it off because they desired more children. Seven women were sterilized, but two of them wished they could have more children even though they acknowledged that sterilization was better in their circumstances. Five women who wanted no more children were not on contraceptives because all contraceptive methods that they have tried gave uncomfortable side effects, they did not know about sterilization, or simply had not made the time to go back to the clinic. Reproductive agency in contraceptive use is illustrated in the quote below.

“...he was a single man when we got married and he wants a child of his own...I really don’t want to have more children. But my husband said, ‘Who will take care of us when we get old?’ I see his point. But I don’t want to have another sick child... I even had an IUD inserted without telling my husband.” (Ratih, 31)

This woman presented a conflict between the beliefs and norms about children, partner expectation, and fear of HIV transmission, within which she exercised her agency in using contraceptives behind her husband’s back. Another woman who believed in the importance of children in a marriage decided to forgo her doctor’s recommendation for sterilization.

“The doctor had recommended me to get sterilized when I gave birth to my second child, but at the time I thought what if I split up with my child’s father and I want to remarry. So I didn’t want to do it.” (Poppy, 33)

These two women illustrated that their opposing decisions regarding contraceptive use were both dominated by their *behavioral beliefs*. Ratih believed she should not have more children to avoid risk of vertical HIV transmission and Poppy believed she should not be sterilized to be able to remarry and have more children.

Access to SRH Services

Restricted access to SRH services serves as a barrier for women to fulfill their childbearing intentions, contraceptive needs, or address other reproductive health concerns.

“It’s been fifteen years since my son was born. I’ve never gotten pregnant [while working as a sex worker] even though I did not use any protection. I wonder if I’m capable of having another child. What if something is wrong with me down there? I actually want to get checked with an ob-gyn but I don’t have a husband. I’ll wait until I have a husband to check.” (Sari, 33)

Sari's decision to postpone seeking gynecology consultation was driven by a *behavioral belief* that ob-gyn specialists would discriminate service to women with no husbands. The same belief made another single woman exercised her agency in a different way: she lied about having a husband in order to get contraceptives, and she kept her HIV status undisclosed.

Perceived discrimination at SRH services were also related to HIV status and sex work. Most women mentioned one particular obstetrician that they visited for antenatal care and delivery, regarded as a HIV reproductive specialist. In fact, counselors and doctors at different HIV clinics in the city referred their pregnant patients to her. Consultations with her at the public hospital has a long waitlist and her private practice is expensive, and a *control belief* that she is the only one capable and willing to care for women living with HIV during pregnancy and delivery forced some study participants to borrow money to access her services. Access to SRH services is more restricted among FSWs, particularly brothel workers. Staff from a clinic managed by a community-based organization visit some brothels for HIV and sexually transmitted infections (STI) testing at regular intervals. Positive cases would be referred to HIV clinics but the FSWs would only go if their pimp or brothel manager took them. Some of them ended up dropping out of ART. A *control belief* to avoid discrimination due to sex work made FSWs who had quit hid their sex work history from any health provider. When fieldwork for this study was finished in 2018, HIV counseling and testing at antenatal care was not standard practice. Staff at an obstetrics ward of a hospital said that sometimes they referred patients for HIV testing based on appearance; wearing revealing clothes or having a tattoo were mentioned as examples. Two midwives with private practice collaborated with a community-based organization for HIV counseling and testing of antenatal patients once a month because they did not feel comfortable talking about HIV themselves with their patients. Their motivation to know the HIV status of their patients was due to concern about potential exposure during childbirth.

Discussion

This study presents the complex reality in reproductive health of WLWH in Indonesia. To fulfill their childbearing intentions women exercised reproductive agency in childbearing, delivery, and contraceptive use. Behavioral and control beliefs played a bigger role than normative beliefs in influencing their intentions. They exercised agency over a landscape of inconsistent and sometimes discriminatory practice of reproductive health policies and socioeconomic barriers. Some of the actions taken

(non-disclosure, concealment of certain procedures) posed an increased risk of HIV transmission to their partner or children.

Access to ART has had a positive influence on childbearing intention of WLWH [31–33]. In the early days of roll-out of ART, family support (or lack thereof) and stigma from family were the main considerations in pregnancy decision in light of potential caretaker for the child in the future in the event of parental death [34]. In more recent years, childbearing intentions are related to the stability of sexual relationship, achievement of desired number of children, and the women's age, suggesting a more optimistic view of HIV survival [35]. But even with ART access, concerns about passing HIV to an unborn child, having pregnancy complications, or advancing HIV infection trumped the sense of pride and dignity that traditionally accompanied motherhood [36]. HIV infection remained a burden in sexuality and reproduction and optimal health care could address conditions that help WLWH to exercise their reproductive agency without increasing risk of HIV transmission [37].

Women in other settings have exercised reproductive agency as a form of resilience in facing undesirable conditions. Unwed single mothers in China concealed certain behaviors in the face of state-controlled reproductive health discourse that penalized them [38]. In our study, non-disclosure of HIV status at obstetrics care was due to an intention to avoid Caesarean delivery. In South Africa, partner violence could make young women secretly take contraceptives and exercise stronger reproductive agency [39]. We found women who despite not having a violent partner nevertheless secretly use contraceptives due to discordance between hers and her partners childbearing desires.

Some women in this study experienced childbearing without pregnancy planning and others had unmet contraceptive needs. Whether a pregnancy is planned or unplanned is not always easy to tell. In one study, only 19% of pregnant WLWH said their pregnancy was planned and more than half are ambivalent [40]. In Indonesia women in the general population also experienced unmet contraceptive needs [12,41]. The success of Indonesian contraception and family planning in the 1990s declined after decentralization of national programs—including decision making in health programs—to municipal and district level in 2001 [42]. Contraceptive coverage among general married women remains higher than other low-and middle-income countries but restricted for unmarried women [43]. Family planning program at the village level in Indonesia were rolled out using women volunteers, typically led by

wives of community leaders who would uphold normative values about womanhood [44]. This might hinder access to program for unmarried WLWH as well as married WLWH who are already marginalized due to other factors (such as injecting drugs, sex work, or poverty). WLWH should be able to access contraceptives at HIV clinics, but even in generalized epidemic settings some HIV clinics only promote condom use and hardly offer other contraceptives [45].

SRH services with supportive attitudes towards WLWH would improve PMTCT understanding and help women make informed reproductive decisions, but providing SRH service for WLWH is challenging even in well-resource settings [46–50]. In our study we identified several challenges in SRH care for WLWH, such as restricted access for unmarried women and FSWs, limited number of SRH service provider perceived to be able and willing to care for WLWH, and midwives' reluctance to discuss HIV with patients. In Indonesia, even among general women population SRH services are only readily accessible for those with higher education and stable income [51]. Most WLWH face socioeconomic marginalization, and compounded with and fear of stigma and discrimination, this influences access to all types of healthcare [52–54]. Internalized stigma has been documented to prevent discussion with health provider [55,56]. FSWs are more often subject to stigma and discrimination and they have limited access to all types of healthcare due to intersectional marginalization [57,58]. At SRH service provider, the norms and values held by SRH providers may challenge their ability to provide unbiased services and lead to discrimination and stigma [59,60]. Even among health workers who support reproductive rights of WLWH, knowledge of safe conception methods are sometimes limited and required training [61]. Integrating SRH services at HIV care could reduce discrimination, increase non-condom contraceptive use, and increase pregnancy planning particularly for FSWs living with HIV [62–65].

Almost all WLWH in our study perceived the need to deliver with Caesarean section and most health providers advised as such. Vaginal delivery is safe when there is virological suppression but this setting lacks regular viral load measurement due to financial barriers and the virological status of most HIV patients remained unknown [66–68]. Many SRH providers do not perform HIV testing thus concealment of HIV status could result in vaginal delivery, increasing risk of vertical transmission. Lack of HIV testing at obstetrics services reflects low coverage of PMTCT. HIV testing at antenatal care was made national policy in 2013, but implementation of this policy is challenged by lack of training for SRH providers particularly for those in private practice [69].

This study has some limitations. Information on the intention and behavior relied on recall and might be subjected to recall bias, but because most of them are life changing (e.g. having a child) we expected recall bias to be rare. The factors presented should be treated with caution because the beliefs elicited might be an afterthought for those who talked about past experiences. In this study we collected additional information from health providers (midwives, obstetricians, gynecologists, HIV counselors) but not from partners or other significant people in the women's life. Studying childbearing intentions on couples instead of women could shed a light on the patriarchal norms that guided decision-making [70]. We also did not analyze the differences for women in discordant or concordant relationship.

However, our results present sexual and reproductive agency of WLWH in Indonesia—a subject that has little been studied.

Conclusion

WLWH exercise reproductive agency in the face of personal and social circumstances that support or oppose their childbearing intentions. In Indonesia, structural barriers hinder access to SRH services that result in persisting fear of vertical transmission, unmet contraceptive needs and unplanned pregnancies, or prompt reproductive actions that increased risk of HIV transmission to their partner or child. Interventions at SRH service providers to reduce stigma and structural discrimination and to improve their understanding of reproductive agency are needed to ensure fulfillment of SRHR for all WLWH.

Abbreviations

ART	Antiretroviral Therapy
FSW	Female sex workers
HIV	Human immunodeficiency virus
IUD	Intrauterine device
MSM	Men who have sex with men
PMTCT	Prevention of Mother-to-Child transmission
PWID	People who inject drugs
RQDA	R package for Qualitative Data Analysis
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
STI	Sexually transmitted infection
WLWH	Women living with HIV

Declarations

Ethics Approval and Consent to Participate

All participants of in-depth interview provided written informed consent while participants of informal interviews provided verbal informed consent. The research received ethical approval from the Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University in Bandung, Indonesia.

Consent for Publication

Not applicable.

Availability of Data and Materials

The datasets generated and analyzed during the current study are available on request from the corresponding author, AR. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

Competing Interests

The authors declare that they have no competing interests.

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Authors' Contributions

AR collected all data, performed initial open coding and data analysis, and drafted the initial manuscript. MNP assisted in data collection, data coding, and contributed to the manuscript. RW facilitated data collection and reviewed the manuscript. ML and RC contributed in conceptualizing the study and writing of the manuscript. ZRH supervised thematic analysis using Theory of Planned Behavior during data coding and analysis and writing the manuscript. KPG supervised data collection, coding, and interpretation, and was a major contributor in writing the manuscript. All authors read and approved the final manuscript.

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Authors' Information

AR conducted this study as part of her work towards a doctoral dissertation.

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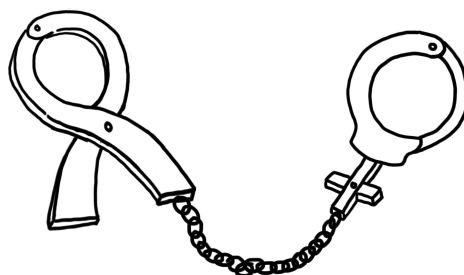
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Chapter 7

General Discussion, Conclusion, and Recommendations



In the early days of biomedical response to the HIV epidemic in Indonesia in the mid-2000s, it was found that injecting drug use among men—that was widespread in Indonesian big cities since the late 1990s—was a predominant route of transmission. HIV prevention in Indonesia has been focused on key populations consisted of PWID (people who inject drugs), MSM (men who have sex with men), and FSWs (female sex workers) [1,2]. As sexual HIV transmission from male PWID to their female partners increased over time, it is assumed that the female partners have no other risk factor than as sexual partner of PWID and would otherwise be categorized as general population. Thus the risk of a concentrated epidemic spreading to the wider community through heterosexual transmission was predicted. At the beginning, prevention of mother-to-child transmission (PMTCT) only targeted vertical transmission from women who got pregnant as women living with HIV (WLWH) [3]. The Ministry of Health developed guideline for antenatal HIV testing for women in general population in 2013 but its implementation has not reached a national scale.

The characteristics of the HIV epidemic among women in Indonesia, and how it relates to their sexual and reproductive health received little attention in the beginning of the HIV epidemic. The studies presented in this thesis were initiated in 2014 with the purpose to improve our understanding. At first, we investigated if the number of female patients that newly presented at a provincial referral HIV clinic increased over time (chapter 2), how they differed from male patients, and what their reproductive history was, in order to understand their role in HIV transmission to the general population and their specific needs with regard to HIV care. From the life history of some of these women and other WLWH, we explored whether structural social inequalities could have contributed to increase their vulnerability to exposure and eventual HIV infection (chapter 3). Thereafter we asked ourselves whether the HIV treatment outcomes of WLWH in Indonesia differs from men (chapter 4), the challenges that WLWH in Indonesia faced in disclosing their HIV status to their sexual partner, how much of the partners are being tested, and the role of healthcare providers in these processes (chapter 5), and finally whether the reproductive intentions of a WLWH in Indonesia are influenced by her serostatus, how much agency she has over her reproductive actions, and her access to SRH services (chapter 6).

In the period from 2007 to 2012, the proportion of new female versus new male HIV cases entering care at a referral clinic increased from 20% to 40% (chapter 2). Considering a total number of 881 female patients, they were slightly younger than male patients (median age 28 vs. 30 years) and entered care in a better clinical

condition and with a much better immune status (median baseline CD4 level 207 cells/ μ L vs. 81 cells/ μ L). Probable route of HIV transmission could only be determined for 48.1% of them, i.e. history of injecting drug use (16.1%), history of sex work (6.6%), and having an HIV-positive partner (25.5%). Most of them were married (60%) or had been married (29%), with a higher proportion of divorced or widowed compared to women of reproductive age in the general population (5%) based on demographic survey data [4]. Unfortunately, data on their sexual and reproductive behavior were incomplete; 43% lacked data on pregnancy status and 76% on history of sex work.

This study showed that even though the majority of HIV cases in Indonesia were still found among men, women make up a growing proportion of those who are HIV-infected, and of those transmitting the virus. This is similar to the situation in other Southeast Asian countries where transmission from men who used drugs to women have been documented [5,6]. The epidemic profile is very different from Sub-Saharan Africa where HIV is more prevalent in women and the contribution of injecting drug use is more limited [7]. From this study, we identified several aspects relevant to HIV care and prevention in women in Indonesia, i.e. lack of data on HIV transmission risk recorded at the HIV clinic for more than half of the female patients, high proportion of the women with potential of remarriage and childbearing (in reproductive age and divorced or widowed), and both men and women diagnosed late in the disease progression (low baseline CD4 levels). We investigated the different aspects in the subsequent chapters.

We examined the social circumstances leading to exposure and eventual HIV infection in a woman's life in Indonesia (chapter 3). This insight is important for HIV prevention strategies that were mostly focused, due to the originally concentrated character of the epidemic, on groups with known HIV transmission risk behavior, i.e. PWID, MSM, and FSW. Health workers in various healthcare providers uphold the heteronormative views regulating sexual and reproductive matters that see traditional marital union as the only acceptable sexual partnership and these views affected their everyday practice. Our findings show that the factors related to HIV transmission risk in women are a product of an intersect between gender norms, poverty, and policies that disadvantage women, as showed in Table 7.1 below. We recommended to improve legal protection of women and to improve access to sexual and reproductive health services for all women regardless of their marital status. Recent published works have acknowledged that gender inequality and non-conformity to restrictive gender norms intersect with other social factors can have negative impact on health

[8,9]. Restrictive gender norms are also reflected and manifested in health systems, including in reproductive health care [10,11]. While societal norms are slow to change, policies and programs can be designed to reduce gender inequality and restrictive norms through multisectoral action, multilevel and multistakeholder involvement, diversified programming, and social participation and empowerment [12].

Table 7.1 Summary of findings and recommendations of chapter 3

Questions	Findings	Recommendations
What are the circumstances leading to HIV exposure and infection in women?	Having multiple partners (multiple marriages, non-marital partners, sex work) preceded by life events that induced a perception of low self-worth: sexual abuse, premarital sex, divorce, sex work	Laws regulating protection for victims of all types of sexual abuse and partner violence should be implemented
What are the factors increasing vulnerability to HIV?	Perception of low self-worth after certain life events were influenced by non-conformity to gender norms that combined with policies and practices that disadvantaged women increased vulnerability to HIV	Methods to improve access to sexual and reproductive health education and services for all should be studied and implemented

These findings have implications for HIV prevention programs. We identified barriers at each stage of the HIV prevention cascade from Hargreaves et al (Figure 7.1) that monitors prevention methods from the proportion of priority population that would benefit from a prevention method, the proportion of priority population targeted that are motivated to use the prevention method, the proportion who can access the prevention method, and the proportion who would effectively use the prevention method [13]. Women who are vulnerable to HIV exposure would benefit from certain prevention methods, but unawareness of risk and lack of access would prevent them to use it. The first of the barriers identified is the invisibility of most of these women's vulnerabilities making them not considered a priority population in current national HIV prevention strategy.

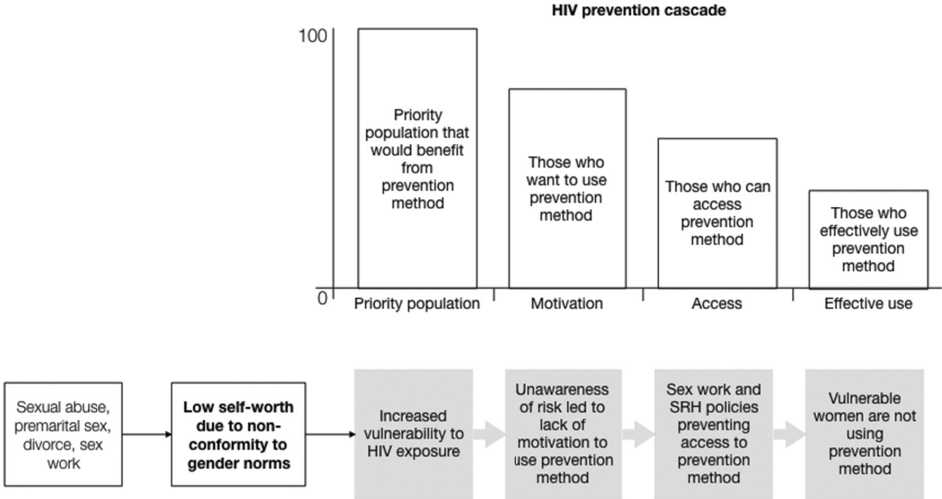


Figure 7.1 Barriers to vulnerable women using prevention method in each stage of HIV prevention cascade from Hargreaves et al.

We then investigated the aspects related to quality of care of HIV treatment (chapter 4), and sexual and reproductive health (chapters 5 and 6) for WLWH in Indonesia.

We analyzed HIV treatment outcomes in female and male patients in a 7-year cohort (chapter 4) involving 3215 patients (33% females), for a total of 8430 person-years (Table 7.2). We found a low uptake of ART in both sexes (59%) and low retention in care (one-year retention 73% in females and 77% in males). Female patients have better survival after treatment initiation, which can be explained by clinical and demographic variables such as disease severity at the time of presentation, education level, and proximity of home address to treatment facilities.

Table 7.2 Summary of findings and recommendations of chapter 4

Questions	Findings	Recommendations
Does ART initiation differ between females and males?	Only 59% of patients diagnosed with HIV initiate ART, both among females and males	The direct link between test and treatment services should be established
How many patients die before and after ART initiation?	4% of patients die before and 6% in the year after ART initiation. Lower mortality in females after ART initiation is explained by lower disease severity at the time of presentation	Strategies for testing subjects at an earlier HIV disease stage should be implemented

Does retention in care differ between females and males?	One-year retention to care was 73% for females and 77% for males ($p = 0.06$). Females have lower retention before ART initiation, mainly due to them having a higher baseline CD4 and higher proportion of them living outside the city. There was no difference in retention after ART initiation between females and males.	Methods to improve treatment retention should be implemented and evaluated
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Besides the differences that can be explained by other characteristics such as disease severity or sociodemographic characteristics, these findings showed that HIV treatment initiation after a positive test in female and male patients at this provincial clinic was similar but low. We also found low ART uptake in both sexes and that feeling healthy limits ART uptake; this group of patients therefore need special attention to keep them in care. Low ART uptake is a challenge even at a higher prevalence setting [14]. Preferences of certain clinic opening hours, clinic crowdedness, shame about diagnosis, and feeling healthy have been associated with delayed ART initiation [15]. A study in MSM and transgender HIV patients in Indonesia showed that those who received ART are more likely to be retained in care, are better informed about HIV, and more likely to have medical insurance [16]. Prompt treatment after testing (testing and treatment) are successful in Indonesian prison setting [17]. Substance use also negatively influence ART uptake [18–20]. Better linkage to care for those diagnosed, accompanied with expansion in ART provision and distribution and better characterization of patients demographic, might help to identify those at risk of lost to follow-up (LTFU) and to ensure appropriate preventive measures [21]. Retention in care is crucial as it reduces mortality and HIV transmission. Reduction of LTFU can be achieved by telephone contact or text messages and stigma support services [22]. A meta-analysis that included our study showed that sex as a risk factor for LTFU is stronger in sub-Saharan Africa than other settings, and LTFU increased among those with vulnerable socioeconomic, clinical condition, and social support [23].

We explored the HIV status disclosure and partner testing of WLWH in Indonesia (chapter 5). Index testing targeting sexual partners, subjects with whom injecting paraphernalia are shared, and biologic children of people living with HIV is effective to increase testing coverage particularly in a concentrated epidemic setting [24]. More testing activities contribute to reaching the UNAIDS target of getting 90% of people living with HIV to know their status. While many HIV-infected women were tested as a

result of partner notifications after their sexual partner was diagnosed with HIV, some WLWH formed new sexual partnership after divorce/death of their HIV positive partner. They remarried, had a new sexual partner, and/or continue sex work. As shown in Table 7.3, decision to disclose the HIV status to sexual partners is influenced by the type and stability of relationship. In polygamous or non-cohabiting relationships, discussion about HIV risk is less likely to happen [25]. Even when HIV status disclosure happened, it did not always lead to the partner getting tested or condom consistently used. More partners are tested when HIV test for WLWH is done at the same day with her partner, which are often the case with HIV testing at antenatal care.

Table 7.3 Summary of findings and recommendations of chapter 5

Questions	Findings	Recommendations
Do women living with HIV disclose their status to their sexual partners?	Decision to disclose their HIV status to the new partner is influenced by the type and stability of relationship and mainly done without any assistance from a health provider	Incorporate counseling in sexual relationships in long-term ART patients and offer assistance for disclosure
Are the partners of women living with HIV tested?	HIV status disclosure does not always result in the partner being tested (54% WLWH have their new partners tested) or condom being consistently used (24% WLWH used condom consistently with their new partner)	Further research to explore various testing strategies: couple testing at antenatal care, provider-assisted partner notification and testing, etc.

These findings implied that increasing coverage of HIV testing in routine antenatal care service could improve uptake of partner testing [26]. Other studies have documented the effectiveness of antenatal care HIV testing with PITC and opt-out approach but this should be conducted with clear informed consent from the pregnant woman and her partner [27–30]. Further research in couple testing at antenatal care may be needed. Another consideration to give serious attention to expanding antenatal HIV testing in Indonesia is its cost-effectiveness [31]. However, caution has to be taken since rights violation has affected pregnant women in the scaling up of HIV testing at antenatal care in another province in Indonesia [32].

A cluster randomized controlled trial in Kenya found that partners were more likely to be tested if the testing was offered immediately after the new diagnosis of the patient than after a 6-week delay, even though there could be a difference in preference from our setting [33]. Partner testing in patients on long-term ART who formed new sexual partnership needs careful consideration, especially during regular HIV treatment visits [34]. The strategy for assisted partner notification services has to be planned

carefully and has to ensure appropriate services combined with linkage/retention programs because substandard service might lead to breach of confidentiality and discontinuation of cART or unconsented disclosure that may increase risk of partner violence [35–37]. HIV status disclosure might not be necessary for partner notification and testing even though all women in our study perceived as such. With the effectiveness of viral suppression in blocking HIV sexual transmission, virally suppressed individuals can fully exercise their right to nondisclosure without fear of imposing transmission risk on their sexual partners [38]. However, in the studied setting in Indonesia, retention in care is low and even among patients retained in care, virological response is not regularly monitored. For treatment monitoring, our study participants felt already burdened with the costs of the cheaper CD4 testing and viral load testing may not even be considered because of the high costs. Status disclosure remains therefore very relevant to the partner and testing is highly recommended. Status disclosure also has other benefits for WLWH such as acceptance and better adaptation to HIV status and good ART adherence [39,40].

Despite the small number found in our study, WLWH who continued to do sex work have a different risk profile than other WLWH. Their diversity of workplace and the many independent sex workers made it almost impossible to have only one type of approach. Our results also showed they have a high sexual mixing patterns with general population, as corroborated by a study in Bali that found FSW have intermittent integration into general population for example through marriage [41]. Compared to other interventions, the evidence suggests condom promotion as most effective to reduce HIV incidence in FSWs and their clients [42]. Therefore it is imperative to reduce stigma against condoms in the general population in Indonesia.

Lastly, we analyzed the childbearing intentions and reproductive agency of WLWH in Indonesia (chapter 6). Due to risk of vertical transmission, childbearing of WLWH becomes a public health concern and not only a private, family, or societal matter. With the wide availability of ART making effective prevention of mother-to-child transmission possible, fulfillment of reproductive rights of women living with HIV should be made a priority. Our findings suggested that WLWH in Indonesia face personal and structural circumstances that either support or oppose their childbearing intentions. In these circumstances some of the reproductive agency exercised in pregnancy, during delivery, or contraceptive use resulted in actions that posed increased risk of HIV transmission to their partner or children (Table 7.4). Structural barriers hinder access to sexual and reproductive health (SRH) services that result in

persisting fear of vertical transmission, unmet contraceptive needs, and unplanned pregnancies. Among the barriers identified are stigma and discrimination at SRH providers, not only towards HIV status but also towards marital status (as perceived by unmarried women) and occupation (as perceived by FSWs). These findings implied that further research and programs should consider ways to overcome HIV stigma and structural discrimination in health services and to improve their understanding of reproductive agency to ensure fulfillment of sexual and reproductive health and rights (SRHR) of WLWH.

Table 7.4 Summary of findings and recommendations of chapter 6

Questions	Findings	Recommendations
What are the factors related to childbearing intentions of women living with HIV?	Behavioral and control beliefs played bigger roles than normative beliefs in supporting or opposing childbearing intentions of women living with HIV	Addressing the beliefs underlying childbearing intentions of women living with HIV in reproductive counseling
What reproductive agency do women living with HIV exercised?	Women living with HIV exercised agency in pregnancy, delivery, and contraceptive use. Some of the reproductive agency posed an increased risk of HIV transmission to their partner or children, e.g. non-disclosure of HIV transmission risk to husband in order to get pregnant or non-disclosure of HIV status to midwife to avoid Cesarean delivery	Acknowledging women's agency in reproductive counseling Provider-assistance in disclosure to partner
How is the access to sexual and reproductive health (SRH) services among women living with HIV?	Structural barriers hinder access to sexual and reproductive health (SRH) services that result in persisting fear of vertical transmission, unmet contraceptive needs and unplanned pregnancies, or prompt reproductive actions that increased risk of HIV transmission to their partner or child	Policy change to remove the structural barriers that hinder access to SRH services (improve access to SRH services among unmarried women, reduce stigma and discrimination from health providers)

Stigma and discrimination in health care settings have deleterious effects. Efforts to reduce stigma and discrimination against PLWH have been shown before in different settings [43]. In countries like Indonesia where behavior related to HIV risks are criminalized, the challenge of overcoming stigma and discrimination is even greater. The presence of stigma and discrimination is also associated with gender inequalities [44]. Hence interventions that address gender inequalities and empower women would help to improve SRHR for all women including those living with HIV [45]. Support groups can be useful in coping with stigma and discrimination from relatives,

friends, and health providers [46]. Our findings suggested that internalized stigma can act as a barrier to access support group or as found in another study, to utilize other services [47]. Further research is needed to assess the effectiveness of support groups, identify other possible barriers to access support groups, and whether other methods to reduce and cope with stigma and discrimination can help people living with HIV. A structural intervention at the policy level is needed in order to prevent discriminatory practices in SRH service.

We also found that in exercising agency to fulfill their reproductive intentions, WLWH sometimes disregarded the advice received from a health worker. This highlighted the need to combine biomedical and social sciences in PMTCT [48]. Focusing solely on interventions at the health provider level based on the assumption that WLWH (or any individual) will act after being counseled has been a great social barrier to effective HIV prevention [49]. PMTCT and any HIV prevention intervention require that people choose to change their social practices. But a change of social practices is not a matter of individual choices. For a successful HIV transmission prevention, the locus of change is not individuals but the social and political medium that enables collective action. Therefore, HIV prevention policies and programs need to be informed by understanding of the cultural, political, and social contexts. A conceptual framework was developed based on the concept of social public health from Kippax (Figure 7.2).

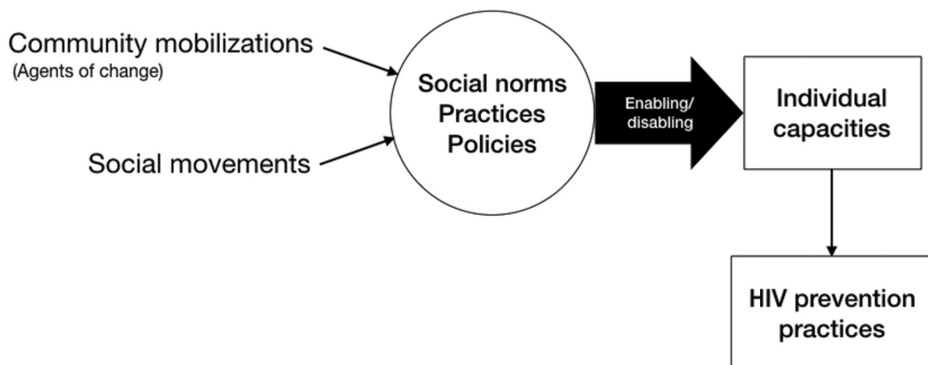


Figure 7.2 The importance of understanding cultural, political, and social contexts in HIV prevention

In the past decade, studies on integration between HIV and SRH have been conducted and HIV programs had been designed to support SRH-related activities, such as the linked response (LR) in Cambodia [50–53]. Research analyzing the integration of HIV with SRH services found that the economic efficiency gain is low although it can

improve productivity if planned in the broader context of human resources planning [54,55]. A possible barrier to HIV and SRH integration in Indonesia is the separate directorates managing the two services within the Ministry of Health (the directorates of infectious disease control and family health) – the two directorates could have different priorities in their agenda [56].

Conclusion and Recommendations

This thesis presented different clinical and social aspects important for the care of WLWH in Indonesia. The circumstances leading to their HIV exposure are influenced by gender norms, poverty, and sexual and reproductive health policies that disadvantage women. At HIV clinic, female patients have different characteristics than male patients and the proportion relative to male patients is increasing. ART uptake is low for both female and male patients, but female patients in care face a better survival. At the same time, females have a poorer retention in care and are therefore at risk for increased morbidity and mortality. Women with longstanding HIV infection may meet new partners but status disclosure and partner testing needs improvement as it is more rare compared to women who were newly diagnosed or tested at antenatal care. They exercised agency in their reproductive action to fulfill their childbearing intentions but sometimes it poses an increased risk of HIV transmission to partner or child. Our results indicate that different gaps exist between the advancement of treatment and actual practice under field conditions in Indonesia, between policies and practices, and between biomedical and social cultural aspects of HIV.

This thesis includes various recommendations. Specific recommendations in HIV care include an early testing for both men and women, the strengthening of linkage between testing and treatment, and the measures to improve retention in care: these recommendations are highly needed as they are likely to result in decreased morbidity and mortality. Data quality improvement at HIV clinics and linkage between different service providers would improve program monitoring and evaluation. Further recommendations are made in order to improve the quality of life of WLWH and ensure fulfillment of their reproductive rights, i.e. access to sexual and reproductive health services for all women, scaling up of antenatal HIV testing, and relationship and childbearing support and counseling for all female HIV patients – regardless of marital and pregnancy status. Rights violation in SRH laws, policies, and interventions is not unique to Indonesia as some other Muslim-majority countries also face a similar issue [57]. Recent development in sexual and reproductive policy in

Indonesia showed a discouraging phenomenon with a new legislation to criminalize extramarital consensual sex is being approved in the parliament [58]. Finally, the importance of addressing stigma and discrimination for HIV prevention has been acknowledged since more than a decade but more remains to be done particularly regarding discrimination in health service policies and program implementation [59]. The rights of WLWH should be upheld as human rights in all programs including the programs involving sex workers [60]. This thesis also adds to the growing bodies of research that shows how social sciences could help HIV prevention policies to move beyond the paradigm of individual behavior change [61]. As these recommendations affect morbidity, mortality, and the quality of life of a large group of PLWHIV in Indonesia, some matters of urgency needs to be considered. We hope that this thesis inspires healthcare workers or policy makers in Indonesia to implement some of the recommendations or initiate further studies where needed.

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Appendix

Summary

Ringkasan

Samenvatting

Methodological, Professional, and Personal Reflexivity

Data Management

PhD Portfolio

Curriculum Vitae

Summary

HIV prevention in Indonesia has been focused on key populations consisted of PWID (people who inject drugs), MSM (men who have sex with men), and FSW (female sex workers). As sexual HIV transmission from male PWID to their female partners increased over time, the risk of a concentrated epidemic spreading to the wider community through heterosexual transmission was predicted. This thesis employed mixed quantitative and qualitative methods to address the questions related to the clinical, epidemiological, and social aspects of HIV treatment and sexual and reproductive health of women living with HIV (WLWH) in Indonesia. We found that even though the majority of HIV cases in Indonesia were still found among men, women make up a growing proportion of those who are HIV-infected, and of those transmitting the virus. There was a lack of data on HIV transmission risk recorded at the HIV clinic for more than half of the female patients, high proportion of the women with potential of remarriage and childbearing (in reproductive age and divorced or widowed), and both men and women diagnosed late in the disease progression (low baseline CD4 levels). The factors related to HIV transmission risk in women are a product of intersects between gender norms, poverty, and certain policies that disadvantaged women. These structural vulnerabilities are largely invisible, making women who are structurally vulnerable not considered a priority population in current national HIV prevention strategy. In HIV treatment outcomes, female patients have better survival than male patients after treatment initiation, which can be explained by clinical and demographic variables such as disease severity at the time of presentation, education level, and proximity of home address to treatment facilities. HIV treatment initiation after a positive test and ART uptake in both female and male patients were low. Retention in care is lower among those with vulnerable socioeconomic, clinical condition, and social support. Some WLWH formed new sexual partnership after HIV diagnosis. They remarry, have a new sexual partner after divorce/death of HIV-infected partner, or continue sex work. Decision to disclose the HIV status to sexual partners is influenced by the type and stability of relationship and HIV status disclosure does not always result in the partner being tested or condom being consistently used. Partners are more consistently tested when the WLWH was diagnosed at antenatal care. WLWH in Indonesia face personal and structural circumstances that either support or oppose their childbearing intentions and some of the reproductive agency exercised in pregnancy, during delivery, or contraceptive use resulted in actions that posed increased risk of HIV transmission to their partner or children. Structural barriers—including stigma at health providers—hinder access to sexual and reproductive

health (SRH) services that result in persisting fear of vertical transmission, unmet contraceptive needs, and unplanned pregnancies. Prevention of mother-to-child transmission (PMTCT) and any HIV prevention policies and programs need to be informed by understanding of the cultural, political, and social contexts.

Ringkasan

Pencegahan HIV di Indonesia selama ini difokuskan pada populasi kunci yang terdiri atas Penasun (pengguna narkoba suntik), LSL (lelaki yang berhubungan seks dengan lelaki), dan PSK (pekerja seks komersial). Seiring waktu, penularan HIV secara seksual dari lelaki penasun kepada pasangan perempuannya kian meningkat, dan seperti yang sudah diprediksi, epidemi yang awalnya terkonsentrasi berisiko menyebar ke komunitas yang lebih luas lewat penularan melalui hubungan heteroseksual. Tesis ini memadukan metode kuantitatif dan kualitatif dalam menjawab pertanyaan yang berkaitan dengan aspek klinis, epidemiologis, dan sosial dalam penanganan HIV serta kesehatan seksual dan reproduksi bagi perempuan yang hidup dengan HIV (Perempuan ODHA) di Indonesia. Kendati di Indonesia sebagian besar kasus HIV ditemukan di kaum lelaki, jumlah perempuan yang terinfeksi HIV semakin meningkat, dan mereka termasuk yang menularkan virus tersebut. Lebih dari separuh pasien perempuan di klinik HIV juga tidak memiliki data risiko penularan HIV, banyak di antara pasien perempuan ini berpotensi untuk menikah kembali dan punya anak (dalam usia subur dan menajanda), dan baik lelaki maupun perempuan terlambat didiagnosis saat kondisi penyakitnya sudah parah (level CD4 rendah). Faktor-faktor yang berkaitan dengan risiko penularan HIV pada perempuan merupakan produk silang sengkabut antara norma gender, kemiskinan, dan beberapa kebijakan yang merugikan perempuan. Kerentanan struktural ini nyaris tak kasatmata, membuat perempuan yang secara struktural rentan tidak dipandang sebagai populasi prioritas dalam strategi pencegahan HIV nasional saat ini. Dalam hasil pengobatan HIV, pasien perempuan memiliki tingkat menyintas yang lebih baik dibandingkan pasien lelaki setelah memulai pengobatan; perbedaan ini bisa dijelaskan lewat variabel-variabel klinis dan demografis seperti tingkat keparahan penyakit saat datang ke klinik, tingkat pendidikan, dan kedekatan alamat rumah dengan fasilitas pengobatan. Baik pasien perempuan maupun lelaki sama-sama sedikit yang memulai pengobatan HIV dan terus mengonsumsi obat ARV (antiretroviral). Retensi dalam perawatan HIV lebih rendah di antara mereka yang rentan dari segi sosial ekonomi, kondisi klinis, dan dukungan sosial. Beberapa Perempuan ODHA menjalin hubungan seksual baru setelah didiagnosis HIV. Ada yang menikah kembali, memiliki pasangan seksual baru setelah bercerai atau ditinggal mati oleh pasangan yang terinfeksi HIV, atau terus bekerja sebagai PSK. Keputusan untuk mengungkapkan status HIV kepada pasangan seks dipengaruhi tipe dan stabilitas hubungan, dan pengungkapan status HIV tidak selalu berujung pada pasangan seks dites HIV atau penggunaan kondom yang konsisten. Tes HIV pada pasangan seks lebih konsisten dilakukan jika Perempuan

ODHA didiagnosis saat memeriksakan kehamilan. Perempuan ODHA di Indonesia menghadapi kenyataan personal dan struktural yang entah mendukung atau menentang niat mereka untuk hamil, dan sebagian dari pengambilan keputusan mereka terkait kesehatan reproduksi—kehamilan, persalinan, atau penggunaan alat kontrasepsi—berbuah tindakan yang berakibat pada meningkatnya risiko penularan HIV kepada pasangan atau anak-anak mereka. Rintangan struktural—termasuk stigma di penyedia layanan kesehatan—menghalangi akses pada layanan kesehatan seksual dan reproduksi (Kespro) yang berakibat pada tertanamnya rasa takut akan penularan vertikal, tidak terpenuhinya kebutuhan akan alat kontrasepsi, dan kehamilan tak terencana. Kami menyimpulkan, kendati secara klinis faktor-faktor yang memengaruhi hasil pengobatan antara lelaki dan perempuan tidak berbeda, secara sosial perempuan dirugikan dengan adanya faktor terkait gender yang memengaruhi kerentanan mereka pada infeksi HIV, risiko menularkan HIV, dan kehidupan reproduksi, dan pada saat bersamaan menyebabkan kerentanan dan risiko ini menjadi tak kasatmata serta sulit dibicarakan. Pencegahan penularan HIV dari ibu ke anak (PPIA) dan kebijakan serta program pencegahan HIV apa pun perlu disampaikan dengan terlebih dahulu memahami konteks budaya, politik, dan sosial.

Samenvatting

Hiv-preventie in Indonesië is gericht op de belangrijkste risicogroepen bestaande uit intraveneuze drugsgebruikers, MSM (mannen die seks hebben met mannen) en vrouwelijke sekswerkers. Aangezien de seksuele overdracht van hiv van mannelijke drugsgebruikers naar hun vrouwelijke partners in de loop van de tijd toenam, werd er verwacht dat de tot dan toe geconcentreerde epidemie zich zou verspreiden naar de bredere populatie via heteroseksuele overdracht. Dit proefschrift gebruikt gemengde kwantitatieve en kwalitatieve methoden om de vragen te beantwoorden die in relatie staan met de klinische, epidemiologische en sociale aspecten van hiv-behandeling en seksuele en reproductieve gezondheid van vrouwen die leven met hiv in Indonesië. Ondanks dat hiv in Indonesië nog steeds het meeste voorkomt bij mannen, laten wij zien dat vrouwen een steeds groter deel uitmaken van degenen die met hiv zijn geïnfecteerd en onder de personen die het virus overdragen. Voor meer dan de helft van de vrouwelijke patiënten in de hiv-kliniek was er geen informatie over mogelijke hiv transmissieroute. Een groot deel van de vrouwen is in de vruchtbare leeftijd en gescheiden of weduwe en dus in de mogelijkheid om te hertrouwen en kinderen te krijgen. Bij zowel mannen als vrouwen wordt de ziekte pas laat gediagnosticeerd (met lage CD4-spiegels). De factoren die gerelateerd zijn aan het risico op hiv transmissie zijn een product van gendernormen, armoede en een beleid dat vrouwen benadeelt. Deze factoren zijn grotendeels onzichtbaar, waardoor vrouwen die dus structureel kwetsbaar zijn, niet worden beschouwd als een belangrijke risicogroep in de huidige nationale hiv-preventiestrategie. Vrouwelijke hiv-patiënten hebben na de start van de behandeling een betere overlevingskans dan mannelijke patiënten, wat kan worden verklaard door klinische en demografische variabelen zoals de ernst van de ziekte op het moment van diagnose, opleidingsniveau en de nabijheid van faciliteiten waar behandeling beschikbaar is. Het aantal personen dat ART behandeling start na een positieve test was laag bij zowel vrouwelijke als mannelijke patiënten. De retentie in de zorg is lager bij mensen met een kwetsbare sociaal-economische status, slechte klinische toestand en/of weinig sociale steun. Sommige vrouwen die leven met hiv vormden nieuwe seksueel relaties na de hiv-diagnose. Ze hertrouwden, kregen een nieuwe seksuele partner na scheiding/overlijden van hun hiv-besmette partner, of zetten sekswerk voort. De beslissing om je hiv-status aan seksuele partners bekend te maken, wordt beïnvloed door het type en de stabiliteit van de relatie. Het bekendmaken van de hiv-status leidt niet altijd tot een test van de partner of tot consequent gebruik van condooms. Partners werden consistent getest wanneer de vrouw die met hiv leeft werd gediagnosticeerd tijdens prenatale zorg. Vrouwen die leven met hiv in

Indonesië worden geconfronteerd met persoonlijke en structurele omstandigheden die hun voornemens om kinderen te krijgen steunen of tegenwerken. Sommige praktijken die vrouwen uitoefenen tijdens de zwangerschap, de bevalling of het gebruik van anticonceptie geven een verhoogd risico op overdracht van hiv op hun partner of kinderen. Structurele barrières - waaronder stigmatisering bij zorgverleners - belemmeren de toegang tot de seksuele en reproductieve gezondheidszorg, wat resulteert in aanhoudende angst voor verticale overdracht van hiv, onervulde anticonceptie behoeften en ongeplande zwangerschappen. We concludeerden dat, hoewel klinisch factoren die de behandelresultaten beïnvloeden niet verschilden tussen mannen vrouwen, vrouwen sociaal benadeeld worden door factoren die het risico op hiv infectie, en de overdracht van HIV vergroten en het reproductieve leven beïnvloeden. Tegelijkertijd zijn de kwetsbaarheden en risico onzichtbaar en moeilijk bespreekbaar door deze factoren. Daarom is het belangrijk dat preventie van hiv transmissie van moeder op kind en het hiv-preventie beleid gebaseerd moeten worden op inzicht in de culturele, politieke en sociale context.

Methodological, Professional, and Personal Reflexivity

When I realized that I needed to use qualitative methods to explore the topic of sexual and reproductive health of WLWH, I did not immediately feel comfortable about it. My previous research experience has been quantitative in nature and I was not confident in my qualitative research skills. My understanding of health and healthcare has been mainly biomedical due to my background as a medical doctor, however I believe combining a social science perspective to the research has not only enriched my thesis but also addressed the research questions with dimensions that are important for the WLWH. I had to learn some social science theories, but one of the biggest learning curves during the research is how to think like a social scientist. At many points during the research and writing of this thesis, I felt unsure of my footing. I still would not consider myself a social scientist, but I am eager to learn more about social sciences in health research in my future endeavors. During the field research, I developed a connection with the study participants and representing their voices in this research has evolved to become a somewhat personal agenda. In some ways, I might be seen as an insider during the qualitative research as I have a common ethnic and religious background with most of the study participants. I was born and grew up in Bandung at the same time as some of the women I interviewed because like them I was in my thirties during the interviews. However, my socioeconomic and education background made me feel more like an outsider as I did not share the same experience nor faced the challenges that they face. Furthermore, my experience living in Europe as a masters student for two years and the many interactions I have had throughout my adult life with people from different cultures and countries had given me the ability to be critical of my personal beliefs. I was fully aware of my position of privilege in the society due to having had medical background and higher education that allowed me to navigate the social landscape with relative ease despite also being a bit of a 'misfit': a thirty-something woman who lived alone with no husband or children.

Data Management

Data management refers to the collection, handling, and storage of data in a transparent and reliable manner according to the FAIR principles to make data Findable, Accessible, Interoperable, and Reusable.

Data collection

- Ethical review and approval were obtained from The Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University, Indonesia for the cohort study (Chapters 2 and 3) and the quantitative survey (Chapter 6) No. 33/FKUP-RSHS/KEPK/Ket./2007.
- Ethical review and approval were obtained from The Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University, Indonesia for the qualitative exploratory study (Chapters 4, 5, and 6) No. 143/UN6.CI.3.2/KEPK/PN/2016.
- Written informed consent was obtained from the participants of the cohort study and survey
- Verbal informed consent was obtained from the participants of the qualitative exploratory study

Data handling

- Clinic data (Chapters 2 and 3) and survey data (Chapter 6) were cleaned and de-identified before data analysis.
- Interview summaries (Chapters 4, 5, and 6) were de-identified before data analysis.

Data storage

- The hard copy informed consent forms of patients included in the cohort data used in Chapters 2 and 3 are stored in a locked archive of the HIV Clinic, Department of Internal Medicine, Hasan Sadikin General Hospital, Indonesia.
- The data files of the work presented in this thesis are stored in a password-protected external hard drive managed by the secretariat of the Infectious Diseases Research Center, Faculty of Medicine, Universitas Padjadjaran, Indonesia. The files are stored in a folder with an accompanying readme.txt file that described the structure.
- The quantitative data generated or analyzed in this thesis are included in the published articles. Due to the sensitive nature of the information, the qualitative data is available on reasonable request to the corresponding authors. A suitable way to share the data will then be sought.

PhD Portfolio

Name	Annisa Rahmalia
Departments	International Health and Infectious Disease, Internal Medicine, Radboudumc Infectious Diseases Research Centre, Faculty of Medicine, Universitas Padjadjaran
Graduate School	Radboud Institute for Health Science (RIHS)
PhD period	2014-2019

Courses	Year	ECTS
Planning and management of reproductive health programmes, ITM Antwerp, Belgium – <i>supported by DGD grant</i>	2014	10
Radboud in'to Languages: Academic writing and presentation, Radboud University, Nijmegen, The Netherlands	2014	0.3
Statistical reasoning for public health 1 (free online course), John Hopkins University	2014	2
Qualitative and mixed methods in international research, ITM Antwerp, Belgium	2015	7
Writing in the sciences (free online course), Stanford University	2015	2
Transforming public health surveillance (online course), Columbia University – <i>supported by National Institute for General Medicine Sciences grant</i>	2017	1
PhD retreat, Radboudumc, Nijmegen, The Netherlands	2018	1
Research integrity in scientific professions (free online course), University of Bordeaux	2018	1
Conferences, symposia, and expert meetings		
B-Ideas (Bandung Infectious Disease Symposium)	2014	0.25
Expert meeting on HIV study protocol, Indonesia Research Partnership on Infectious Disease (INA-RESPOND) – <i>with Dr. Rudi Wisaksana</i>	2016	0.25
B-Ideas (Bandung Infectious Disease Symposium)	2016	0.25
Science Day 'Infectious diseases & global health', Radboud Center for Infectious diseases (RCI), Nijmegen, the Netherlands	2017	0.25
Workshop on partners of key populations' vulnerability to HIV and STI transmission, West Java Provincial Health Office – <i>on behalf of Dr. Rudi Wisaksana</i>	2017	0.7 ^a
3 rd Asia Pacific AIDS & Co-Infections Conference (APACC), Hong Kong	2018	0.5 ^b
5 th Global Symposium on Health Systems Research, Liverpool, UK	2018	1.5 ^a
68 th Annual Meeting, American Society of Tropical Medicine and Hygiene, National Harbor, Maryland, USA	2019	0.5

Others		
Various seminars and lectures (e.g. Raboudumc, Radboud University, ITM Antwerp, Faculty of Medicine Padjadjaran University)	2014-2018	1.6
Various workshops (e.g. Radboudumc, Faculty of Medicine Padjadjaran University)	2014-2018	1.6
Reviews of scientific publication	2017-2019	0.3
Total		32

Legend: ^a Oral presentation; ^b Poster presentation

Curriculum Vitae

Annisa Rahmalia was born in Bandung, Indonesia on September 20, 1980 and grew up with her parents and three siblings. Following graduation from medical school in 2005 she joined a tsunami response team in Aceh, where she developed interests in public health programming and preventive medicine. During this period, Dr. Bachti Alisjahbana encouraged her to pursue a postgraduate degree. Her first introduction to issues related to HIV and vulnerability was during a short course in Food and Nutrition Security in Wageningen, The Netherlands in 2009 that she attended with an NFP fellowship. Later that year she received an Erasmus Mundus scholarship for Europubhealth – a European joint masters degree at the University of Sheffield, UK and Ecole des Hautes Etudes en Sante Publique (EHESP), France. She did an internship at Institut Albert Bonniot, Joseph Fourier University, Grenoble, France under the supervision of Dr. Remy Slama and completed her dissertation on the role of placenta in pregnancy exposure to atmospheric pollutants. She was introduced to Prof. Andre van der Ven and Prof. Reinout van Crevel in 2012. She received an NFP grant for her PhD in 2014 with Prof. Andre van der Ven and Prof. Reinout van Crevel as her promoters and Dr. Rudi Wisaksana as co-promotor. She obtained valuable insights on reproductive health and HIV at a short course in ITM Antwerp led by Prof. Marie Laga that she attended under a DGD scholarship right before the commencement date of her PhD. In 2015 she learned qualitative research skills and social science in health research from Prof. Koen Peeters and the Medical Anthropology Unit (MAU) team at ITM Antwerp. Both remained involved in supervising her PhD work and Prof. Koen Peeters became a co-promotor. Annisa is currently involved in an implementation study that uses social science in malaria treatment in collaboration with Prof. Koen Peeters and Prof. Ric Price from Menzies School of Health Research in Darwin, Australia, which brought her to Indonesian Papua.

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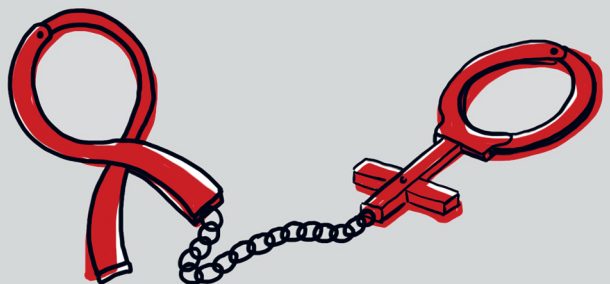
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Annisa Rahmalia

Clinical Care and Sexual and Reproductive Health of Women Living with HIV in Indonesia

Dissertation to obtain the degree of doctor from Radboud University Nijmegen
The Netherlands



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