Life and death with HIV/AIDS: life stories from Karawang, West Java
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Chapter 7

Children are the Future

The desire to become parents

Reproduction among Odha is a poorly addressed issue, largely due to the notion that parenthood is not appropriate for them (Paiva et al. 2007). As Paiva and colleagues argue, being HIV-positive does not fit the image of spouse, wife-mother, or husband-father (2003:98). In the context of health services, Berer (2003:8) states:

AIDS treatment centres rarely provide or refer HIV-positive women for contraception or abortion services or even recognize that men and women whom they identify as at risk of HIV/STIs, such as injecting drug users or sex workers, may need a broader range of sexual and reproductive healthcare. HIV-positive men, meanwhile, are often not seen as fathers with children or as having needs of their own for information and support in this regard by AIDS referral centres.

Motherhood is the socially sanctioned ideal for Indonesian women. Having children provides a woman with a social identity and guarantees her status in her family and kin group. To a certain extent, motherhood also has an economic basis in that it guarantees support from her husband, especially in the event of divorce. For a man, marriage and having children are status symbols; he demonstrates his masculinity and virility and is recognized as the family head.

The effectiveness of ARV treatment brings hope to many Odha to lead normal lives, from working to marriage to having offspring. In the focus group discussions conducted for this research, almost all Odha – particularly those who were of reproductive age – revealed their intention to have children:

I want to have [a] child because it’s a gift. A gift from God. A blessing, right? I’m a widow, wanting a spouse, [to be]
married again. Why not... also to have a child, though we are HIV-positive? We are moving forward! (Vera, age 28).

My friends told me just to get married, if finally I find my mate, having kids is easy... they will help. I think it may prevent infection by not breastfeeding my baby when he's born. Well, caesarian section. I actually want to ask you, if I take the medicine during the pregnancy, is there any directions for use? How can the HIV infect the baby? Does my baby need to take the medicine as well? (Dina, age 26).

I want to have another child, especially a girl.... Because my husband is positive and I'm positive, how can I have another child? I'm afraid my child will be infected. So, I am just rethinking it now. I want to have two children (Euis, age 24).

I'm worried if I have a child. I really want to have a child, but [I am] still worried. I'm afraid because I don't know [whether] my CD4 is high or low. If we are pregnant our CD4 must be high. If it is low we can't get pregnant, right? That's why I'm worried (Nani, age 31).

The excerpts above illustrate the worries and confusion among HIV-positive women regarding their desire to have children. They need more information on how to meet their desire for parenthood without transmitting HIV to the child.

Similar fears and confusion were evident among HIV-positive men, whether they were married or single:

I have plans to have one more child. But waiting till my CD4 count [is] high. Last time I checked it was 375. My wife doesn't mind to have one more child as long as [it is] not HIV-positive (Budi, age 29).

For the second marriage I want to have [a] child. I was married in 2002. It broke off because her parents found me injecting [drugs]. But thank God my wife and kid were not infected... (Arief, age 28).

I'm thinking that too. How [about] if we get married? It's impossible to be covert about our status. That's what makes us confused. I want to [be] married. They said if [I] want to have [a] child the CD4 must [be] above 400, and
viral load\textsuperscript{74} must [be] some million copies, undetectable (Yoyo, age 25).

Actually, Luki doesn’t want to have children because he’s worried that he will infect his wife and the baby later. But his wife really wants to have children even though she knows the risks of getting infected herself. Luki hasn’t completely understood the PMTCT program. He’s only heard about sperm washing to prevent HIV infection from mother to child. Frankly speaking, if there is a chance to have children without HIV, he wants to have a baby girl. At this moment, his CD4 count is still lower than 200, if it is higher than 400, they may try to have a baby (focus group notes).

The desire to have children coexists with worries of infection, concerns about one’s CD4 count, and a rights-based consciousness often encountered among networks of \textit{Odha}, particularly within support groups and NGOs. All \textit{Odha} I met and interviewed had been affiliated with the Pantura Plus support group and YPI, though the extent of their involvement varied. Becoming informed about HIV/AIDS, counseling and treatment, and talking and interacting with other HIV-positive individuals exposed them to the possibilities of living normal lives. The trainings, workshops, and meetings also indirectly became places for \textit{Odha} to seek and find their soul mates, particularly for those who were single or widowed. Some \textit{Odha} perceived that having an HIV-positive spouse would simplify things. The support group moreover influenced their desires for parenthood; though PMTCT services were not yet available in Karawang, YPI provided updates on the advances in PMTCT technology.

\textit{Odha} who doubted or had no intention to have children – whether their partner was HIV-positive, negative, or had an unknown status – gave various reasons for not wanting children of their own. Poor understanding of HIV/AIDS, the priority to raise existing children, and fears of infecting the child were among them.

\textsuperscript{74} Viral load is a blood test that measures the amount of active HIV in one’s blood. The higher the value, the more active HIV is present.
me’. But he still doesn’t believe I’m positive. I used injection contraceptive before (Juariah, age 32).

Not any more. I already have three children from [a] former marriage. Now there is Pendi [his wife’s son] (Alim, age 35).

Not any more. I’m more inclined to [focus on my existing] children. After knowing my husband is HIV [positive], [I] don’t want sexual intercourse any more (Sinta, age 26).

For example, I told him I don’t want to have more children. So if he marries me, we won’t have children because I know how it feels, I’m afraid my baby will get HIV too. It’s true there’s a prevention program, but it doesn’t give a 100% guarantee to what will happen in the future (Yati, age 32).

These worries and ambiguities reflect the need for more appropriate information.

Reproduction is a complex issue for Odha, particularly women. HIV-positive pregnant women in Indonesia can in principle obtain free ARV medicines – nevirapine, for instance – and are offered caesarian deliveries. Since they often find out their serostatus late in their pregnancies, abortion is rarely an option (while abortion is illegal and considered morally unacceptable in Indonesia, traditional as well as modern services are informally available). HIV-positive women thus face a string of reproductive choices: whether to get pregnant, the right time to do so, regarding abortion, antenatal care, caesarian versus normal delivery, breastfeeding versus formula milk, ARV treatment, and condom use as protection against re-infection. For HIV discordant couples (couples in which only one partner is HIV-positive), reproduction entails greater risks of infection.

The HIV epidemic has clearly medicalized the reproductive lives of Odha. They have to learn about biomedical technicalities such as the CD4 count, re-infection, caesarian section, and ARV treatment to be able to make informed decisions. Though many could not afford to take the test, the CD4 count was a key marker of health among the Odha I interviewed. It represented leading a ‘positive life’, particularly for those on ARV treatment keen on having children in the future.
The desire of Odha to have children has significant implications for the transmission of HIV to sexual partners and newborns. Current estimates indicate that women now account for about 52% of the 33.4 million people living with HIV worldwide, compared to 41% in 1997 and 35% in 1985. The proportion of women living with HIV in Asia rose from 19% in 2000 to 35% in 2008 (UNAIDS 2009). In Indonesia, the cumulative number of reported AIDS cases grew from 2,682 in 2004 to 19,973 in December 2009, with women making up 25% of all reported cases (National AIDS Commission Republic of Indonesia 2009:1). These trends mean that there are now many more HIV-positive women of reproductive age, leading to increased numbers of HIV-positive children. However, advances in prevention of mother-to-child transmission (PMTCT)\textsuperscript{75} technologies have meant that, when followed, the probability of transmission can be cut to about 2%. PMTCT programs have hence been implemented worldwide.

Critics in recent years have argued that PMTCT programs, by focusing on the prevention of transmission to children, have provided insufficient care and support to mothers. Critics have also debated the pros and cons of mandatory and voluntary testing, and opt-in and opt-out schemes for pregnant women (Zivi 2005).

As discussed in Chapter 2, the local implementation of Indonesia’s national PMTCT policy, launched in 2006, has been slow and uneven. PMTCT services in Indonesia have been donor and NGO-driven; even before the national policy was released, the Jakarta-based NGO YPI took the lead in a pilot project providing comprehensive PMTCT services in several provinces. Before this pilot project, PMTCT services were primarily available in a few national hospitals in Jakarta, which focused on prong 3 (preventing HIV transmission to the child) and prong 4 (care, support, and treatment for HIV-positive mothers and their families) of the World Health Organization’s guidelines.

Chapter 3 recounted how HIV/AIDS-related health services in Karawang remained limited during the time of this study. Odha therefore turned to YPI and Pantura Plus for information and services, though they often had to travel to hospitals in Jakarta to receive them. For HIV-positive women, pregnancy means that they

\textsuperscript{75} PMTCT technology became central in the global public health discourse in the late 1990s, though at that time it was still expensive and often unavailable in third world countries.
must seek health services to prevent transmission to their children. This chapter discusses the pregnancy and delivery experiences of several HIV-positive women, and the factors that informed their decisions. I argue that pregnancy and giving birth are ways for HIV-positive women to contest HIV/AIDS-related stigma in the family and community; through marriage and having children, they regain control over their reproductive lives and pave the way to ‘normalcy’. 

Safe pregnancy, safe delivery

The reproductive desires of Odha must be understood within wider kinship, gender, and social contexts. Both HIV-positive men and women in this study sought recognition as ‘normal’ people. For HIV-positive women, pregnancy and giving birth meant meeting the socially expected gender roles for adult women. HIV-positive men desired to become household heads and fathers, to prove their virility and to be recognized as adult men. Marriage and reproduction were thus arenas of contestation to challenge HIV/AIDS-related stigma.

The absence of a PMTCT program in Karawang during the study period encouraged HIV-positive women to look for information and services from different sources. Some participated in prevention programs or trainings and workshops delivered by Pantura Plus and YPI, where they could obtain up to date information on HIV/AIDS. Nevertheless, the services delivered by YPI, Pantura Plus, and Klinik Kita – VCT, STI screening, needle exchange for IDUs, ARV therapy, and support groups – did not really address the needs of HIV-positive pregnant women. Family planning and sexual and reproductive health services for Odha were virtually unavailable; counseling services for HIV-positive couples was far from adequate. The three VCT counselors in Karawang lacked the knowledge and skills to deal with the problems and questions of Odha’s sexual and reproductive health, including the prevention of mother-to-child transmission of HIV.

One day, Arif – a counselor at YPI – told me about his difficulties in answering questions from a female Odha. She had asked him what she should do if she wanted to have a child. Arif could not really answer. He admitted that he knew little about
PMTCT and reproductive health, even though as an HIV counselor he was expected to give such advice. Bahrul – a Pantura Plus counselor – faced a similar situation when questioned during post-test counseling about whether the client’s six month-old baby was likely to be infected, and how the baby should be tested. His client had just found out that she was HIV-positive – she was likely infected by her husband – and had been breastfeeding her baby from the start. Bahrul answered that the baby might be infected and advised her to switch to formula milk. But he did not know how the baby should be tested. He promised that he would look into the matter.

Mother and child health services are widely available in puskesmas, hospitals, private clinics, and through private midwives. But for HIV-positive women, these services do not adequately meet their family planning and/or routine prenatal care needs, as we will see below in the stories of Maryam, Leni, and Nani. Ensuring a safe delivery that prevents the transmission of HIV from mother to child requires greater effort.

Budi and Leni – both HIV-positive – married in early March 2007. Leni immediately became pregnant but miscarried after two weeks. Before marrying Budi, Leni was a widow and had an HIV-positive son. Her first husband, an IDU, had died of AIDS several years before; she learnt her seropositive status a week after her husband passed away. Leni wanted to have another child because she was afraid that her son would not survive for long. Shortly after her miscarriage, she became pregnant again. During this pregnancy, she was regularly examined by a private midwife.

I just go to [a] midwife near [my] house. It's cheaper than the doctor. As long as my pregnancy is fine, I don't go to [the] doctor. I don't disclose my [HIV] status though I ask her how Odha who want to deliver are treated. It seems she knows about it. She said that as long as UP [Universal Precautions] is practiced [there is] no problem.

Leni sometimes visited the midwife at puskesmas Karawang, where Budi worked as a case manager for the HIV/AIDS prevention program. Leni herself had been engaged in YPI’s TOP Support group in Jakarta, which made her knowledgeable about PMTCT. She and Budi were convinced that they could have an HIV-negative child if they had access to PMTCT. Leni had also been on ARV
treatment since mid-2006. At the onset of pregnancy, she contacted YPI Jakarta asking if they could help her to access PMTCT services, particularly for the delivery and post-partum care. YPI, however, had no more funding to deliver PMTCT services; the Global Fund had temporarily halted its aid due to mismanagement and a conflict of interest at the Ministry of Health. YPI could only promise to provide formula milk for one year.

At the end of September 2007, Leni’s four year old son died of AIDS in Jakarta. She seemed to accept her son’s destiny. She had no complaints with her new pregnancy and, with Budi’s consent, decided to deliver with the help of a private midwife. They chose a normal delivery simply because they could not afford a caesarean section, which would cost about Rp. 5 million (US$ 555); a normal delivery with a midwife was about Rp. 800,000 (US$ 88). One day in December 2007 I received a text message from Leni:

Brother, how are you? This is Leni. I want to let you know that I delivered on Monday, at 5:30 AM, in the normal way. Though there was a little problem.

I replied to her message by asking where she delivered the baby. Her answer:

At [the] midwife near [my] house. The sex is female. But [I’m] a bit worried about [the HIV] status of the child because at 18 months [she] will be tested. Her name is Risa Putri.

The next day I visited her. Leni and Budi lived in a cramped 2 x 2.5 meter rented room, too small for two adults and a baby. A mattress lay on the floor, a basket for clothes in the left corner, and some cooking pots in the right corner near the door. Posters with HIV/AIDS information were on the walls. Leni told me that on Monday at 3:00 AM she had felt pains in her stomach as if she needed to go to the toilet. Budi immediately took her to the midwife and in less than an hour she delivered the baby. She said that her water had not yet broken when the baby came out.

Although Leni made use of her AIDS activist network to try to access better services, this did not materialize except for formula milk. Her limited financial means limited her choices for delivery, excluding the option of a caesarean section. She resorted to a
private midwife who was perceived as accessible, affordable, and safe despite the risk of transmission during delivery. She and Budi only hoped that her ARV treatment would lower the risk of transmission during pregnancy. Budi once told me that if an HIV-positive woman has good ART adherence and becomes pregnant, the baby is less likely to be infected even through normal delivery. He knew Leni had good ART adherence. Leni was aware that her decision was a gamble and a reproductive risk. Fortunately, her gamble paid off. When I visited Leni at her parent's house in Jakarta in October 2008, her daughter looked healthy and active. Budi told me his daughter had tested HIV-negative.

Nani’s quest to access PMTCT services had a different trajectory. After miscarrying in early April 2007, she became pregnant again in June. Her desire to have a child was undeniably strong and she immediately began searching for information on PMTCT. Nani had high hopes that YPI could provide the service. From what she had learnt, she believed that the best solution was a caesarean section, though she remained unsure about her course of action – normal or caesarean delivery – until her pregnancy’s third trimester. Nani also often worried about her CD4 count, which was never above 300 despite her rigorous adherence to ARV therapy since 2004. Every month she went to a midwife, whom she knew through her outreach work, to check up on her pregnancy in puskesmas Karawang. She also drank Prenagen formula milk for pregnant women. Alongside YPI, Nani sought PMTCT services at PKBI Bandung, where she had a good relationship with a staff member.

I called Mrs. Nunik in PKBI Bandung, asking if I can get PMTCT. But she said [the] PMTCT [program] has stopped because there are no more funds from [the] Global Fund. She promised if there is a new program she will let me know.

In early November 2007, I accompanied Nani to consult with Professor Samsuridjal at Dharmais hospital. She was relieved when the doctor wrote a referral letter to Pokdisus AIDS at RSCM hospital to provide PMTCT services for her delivery. In addition, the doctor asked her to do a free viral load test. Two weeks later, Nani, accompanied by a staff member from Pantura Plus, went to Pokdisus AIDS to register for the PMTCT service. But the hospital
could not provide free delivery services for HIV-positive pregnant women. Nani would have to pay Rp. 4.1 million (US$ 455) if she wanted a caesarean delivery. She was disturbed. ‘Where can I get the money?’ was her text message to me.

Nani’s colleagues at Klinik Kita advised her to arrange for SKTM (a letter certifying her low income status) so that she could obtain benefits from Askeskin (health insurance for the poor) in the hospital later. Although she was not a legal resident of Karawang district, her colleague was able to arrange the SKTM. In the second week of January 2008, she went to Pokdisus AIDS again to obtain free medical services.

I felt pain in [my] stomach three days in a row. Perhaps I’m too tired. My legs are swollen. Then I told Arif. He said it’s better [to] go to Jakarta than stay here…. The doctor suggested caesarean on the 17th, last Thursday, before he saw the USG\textsuperscript{76} result…. But my pregnancy is only 34 weeks. My Hb [hemoglobin] is also low.

The doctor suggested to Nani that she stay in Jakarta until the time was right for a caesarean. The ultrasound showed that the baby had low weight; the doctor advised her to wait a few weeks. She remembered that her first baby was only 1.5 kilos at birth. Nani stayed at the YPI office in downtown Jakarta. Once a week she went for a check up at the hospital, accompanied by YPI staff. Finally, on 12 February 2008, she delivered a baby boy named Rizki Maulana; Rizki means ‘fortune’ and Maulana means ‘honor’. Over time I lost contact with Nani because she returned to her village in Cianjur. One day in 2009, I received a text message from her out of the blue. I called her up. She said that everything was fine in her life and that her son had been tested. He was HIV-negative and was growing up well.

Several factors contributed to Nani’s choice for a caesarean delivery. First was her knowledge about PMTCT, obtained through two years’ engagement with a support group and HIV/AIDS prevention program. Second, she made use of her professional network which helped her to obtain SKTM and Askeskin for free medical services. Third, social and psychological support from

\textsuperscript{76} USG stands for ultrasonography, a diagnostic imaging technique to visualize internal organs.
Pantura Plus and YPI helped her to navigate hospital bureaucracy. Fourth, she received financial support from her employer during her maternity leave, including full salary and transportation costs when returning home from the hospital.

Leni and Nani had something in common: their first child had died of AIDS. They felt the cultural imperative to be a wife and a mother – and to produce a child right after marriage, despite other factors that might influence their reproductive decisions. Childbearing would result in a fulfilling life for them and their children. As Van Hollen (2007: 40) states, HIV-positive women are:

entitled to motherhood as was any other women and their children should have the opportunity to live lives that were just as satisfying as those of any other children.

Allen (2004) argues that the biomedical perspective on maternal health differs from that of individual mothers for it focuses on the risks of motherhood – witness the Indonesian Safe Motherhood Strategy (2004:10) – and not risks to motherhood. Following this distinction, the prenatal care practices observed by Leni and Nani concerned risks to motherhood, with ‘conditions that prevented them from carrying a pregnancy successfully to term’ (ibid. 2004:186). Nani had previously miscarried; both women had lost a child to AIDS. Attaining motherhood was thus a way for both to contest HIV/AIDS related stigma: as HIV-positive women, they demonstrated their ability to construct lives that looked ‘normal’ to their partners, family, and community.

**Sterilization: between coercion and consent**

Female sterilization, though unpopular, is among the methods used in Indonesia’s family planning program. Doctors have been advising post-partum sterilization to HIV-positive women since before the inception of the national PMTCT program in 2006. In my research, I came across several HIV-positive women who had consented to sterilization after undergoing caesarean section at Jakarta’s RSCM hospital.
Candra from Jakarta – a mother who ran a small store – recounted that after giving birth to her second child a year ago, a doctor in the central hospital advised sterilization. ‘The doctor said that I should be sterilized because my husband and I were both [HIV] positive’, she said. But instead of asking her opinion, the doctor talked to her husband in private. Since her husband was concerned they would face difficulties accessing the PMTCT service otherwise, he signed the consent form without Candra in the room.

In contrast to Leni and Nani, who were engaged in AIDS activism and exposed to information on PMTCT, Maryam – a single mother of two daughters – only rarely came to support group meetings. She knew almost nothing about PMTCT when she became pregnant. Maryam went to puskesmas Rawamerta for antenatal care from the third to the fifth month of her pregnancy; in the eighth month, she came to YPI Karawang to inquire about delivery options for HIV-positive women. Maryam recounted her experience when she underwent a caesarean section at RSCM hospital in early August 2005.

I was eight months pregnant when [I] went to Jakarta for caesarean. I stayed at [the] YPI workshop. I was asked to take neviral medicine before [the] caesarean. I had to take it at 6 AM, 9 AM, and 12 PM…. Once I made [a] mistake when taking [the] medicine. I was scared of [the] operation, scared of dying. I had two children but [had] never been operated. I just prayed. It’s frightening. I was sedated but only half [of my body]. So I [was] awake, could feel what was happening. My husband didn’t come. He already had another woman. I felt scared when the baby was taken, like my heart was pulled. [I was] breathless. Oh, I’m dead, I was scared…

Right before the caesarean section, the doctor asked her whether she agreed to be sterilized after the surgery. Maryam recounted her experience:

No, I was sterilized with the consent of YPI…. But the doctor said ‘You [will] not [be] totally sterilized. Only tied up a bit. Probably you can have [another] child, sometimes you can’t. Yeah, only half… not totally tied up…’ I signed it [informed consent form] when [the] operation was about to [be] carried out. I signed [it] because my husband was not there.
Nani had a similar experience when she underwent caesarean surgery. Before she entered the operating room, the doctor asked about sterilization and briefly explained tubal ligation. Nervous about the impending operation, Nani simply agreed with this medical recommendation without further consideration.

The national coordinator of Ikatan Perempuan Positif Indonesia (Indonesia Alliance of Positive Women), speaking to the Kompas newspaper on 3 December 2010, stated that advice for post-partum sterilization was common in city hospitals when both husband and wife were HIV-positive. In a similar vein, two studies in Brazil revealed that respectively 51% (n=154) and 36% (n=130) of HIV-positive women who attended prenatal clinics in São Paolo (Hopkins et al. 2005) and Ceara (Oliveira et al. 2007) were sterilized post-partum. In Thailand, this figure was 56% (cited in Oliveira et al. 2007:1261). In all of these studies, the woman’s HIV status was the main reason for sterilization, while healthcare providers played an important role in influencing women’s decisions.

Maryam and Nani’s ‘decisions’ were likely made or strongly influenced by their doctors, since they themselves were not well informed about – or planning to undergo – sterilization. Nani, who had been involved in the HIV/AIDS prevention program for two years, had little knowledge of this procedure, perhaps reflecting the lack of contraceptive counseling in HIV/AIDS services more generally (Berer 2003). Institutional and medical cultures also played important roles. Doctor-patient relationships tend to be unequal, and the ‘advice’ of doctors very often takes precedence over the patient’s own wishes and expectations. Candra hoped that HIV-positive women in the future would never have to endure her ordeal. ‘Don’t force women to be sterilized. Women have the right to have a family, children, and grandchildren’, she said.

Regarding the mode of delivery, Indonesia’s PMTCT guidelines recognize the right of HIV-positive pregnant women to decide for themselves after counseling (Departemen Kesehatan RI 2006:31). Medical discourse, however, strongly encourages health providers to recommend caesarean section. Mr. Jajang, a doctor from the Family Health Division of Dinkes Karawang, stated:

If an Odha gets pregnant, wants to have a child, [it’s] no problem. To keep the baby from getting infected, there is [a] delivery program. Delivery must [be] caesarean section. It’s a must…. With c-section the baby may not [be] infected
because there is [the] placenta barrier…. Therefore, it’s absolutely with c-section…. When talking about PMTCT, first, [a] hospital for delivery must [be] available. Then milk substitution, ARVs for babies, ARVs for mothers, it’s complex.

The above suggests that although their right to decide on the mode of delivery is formally recognized, HIV-positive pregnant women in reality have little choice.

**Discrimination in the health services**

Studies in different countries have shown that *Odha* often encounter stigma and discrimination in the health services (Li 2007; Poindexter 2007; Gogna et al. 2009). Forms of discrimination vary, ranging from refusal to treat *Odha* to differential treatment, physical isolation, or disclosure of their HIV status to others in breach of confidentiality. *Odha* in Indonesia can be discriminated against in two ways: as an *Odha*, and for being poor if he/she uses Askeskin to obtain free health services. As I have shown in previous chapters, many *Odha* in Karawang come from lower socio-economic classes, whether they are sex workers, IDUs, migrant workers, gays, *waria*, or the sexual partners of *Odha*.

Discriminatory behavior in the health services was admitted by some healthcare workers in this study. Some said they were not prepared to treat *Odha*, citing lack of medical equipment, but it more often had to do with their lack of knowledge on HIV/AIDS and their perception of the illness. One day I came to RSUD Karawang to meet Bahrul, a VCT counselor at Pantura Plus. He had been called by a health worker from a TB ward, who asked him – as a favor – to provide VCT to a patient suspected of HIV. The patient was a woman, an ex-migrant worker, who was severely ill. Bahrul told me that he had done VCT for ‘HIV suspect’ patients several times in this hospital. How the health workers viewed these patients was evident in how they communicated to them. To the men they often asked, ‘Did you ever use it?’ – referring to injecting drugs. To the women,
they asked, ‘Are you TKW?’\textsuperscript{77} or ‘Where do you work?’ – the latter implicitly referring to sex work. A male nurse in a TB ward stated:

We are afraid of [getting] infected too. We don’t know who is positive, only suspects…. Yeah, we also [have] less skill to take care [of] Odha. Lack of information. For services I think there’s also limited budget…. Like for disposable gloves or masks….

Although RSUD Karawang appointed an HIV/AIDS working team (\textit{kelompok kerja} or \textit{pokja}) in 2006, a doctor in the emergency unit – and a member of the team – explained why the hospital could not test for HIV.

No, not available yet. We don’t have reagent for [the] test. There was an offer for [the] rapid test. We declined it…. This is about [a] decision for somebody that until now there is no medicine yet [to cure HIV]. It is expected that our decision is closest to the truth. So we decide to send [blood] to Prodia\textsuperscript{78} for Elisa\textsuperscript{79} test and its cost [is] charged to [the] hospital.

An official at \textit{Dinkes} Karawang argued that the local government could not address HIV/AIDS alone; it needed the aid of NGOs, particularly for care and support.

We have to sit together. Like KPAD…. Now when there is [an] HIV-positive case we argue [with] each other…. Where [the] ambulance [comes] from, what hospital, who will pay, then how about home care…. We don’t have [a] standard procedure yet. That’s what we need….

\textsuperscript{77} TKW (\textit{tenaga kerja wanita}) is a female migrant worker. I discussed this issue in Chapter 3. Karawang is a leading sending area of TKWs to the Middle East.

\textsuperscript{78} Prodia is a private laboratory.

\textsuperscript{79} Elisa (enzyme-linked immunosorbent assay) is usually the first test used to detect HIV infection. If antibodies to HIV are present, the test is usually repeated to confirm the diagnosis (http://www.webmd.com/hiv-aids/human-immunodeficiency-virus-hiv-test) (accessed 1 August 2011).
Odha shared their experiences with health services in a focus group:

Usually health workers don’t know their own regulations. UP [Universal Precautions] for example, they have to wash their hands first. That’s for their own sake too. Or when taking blood [they] must wear gloves. I think it’s because of lack of information and education for paramedics… (Budi, age 29).

I went to Doctor X. My CD4 [was] still 350 but I didn’t feel good. [I] often felt weak. I had [swollen] lymph nodes, so I checked with Doctor X. He said that I must take ARVs because I had [swollen] lymph nodes. When I returned to the first doctor, he said don’t take it because my CD4 [is] still above 200. I’m confused! (Robby, age 25).

These excerpts point to inconsistencies in the treatment of HIV-positive patients. When Nani experienced her miscarriage, she was referred to the maternity ward at RSUD Karawang. I stayed outside while Budi accompanied her inside the ward. When he came out, he told me that a nurse had wanted to take Nani’s blood without wearing gloves. Budi questioned her about this; the nurse asked him why. Budi replied curtly, ‘That’s the rule, right? UP.’ The nurse nodded and used gloves.

Leni’s experience with the midwife also revealed much about healthcare providers’ responses to HIV cases. Before the midwife handled the delivery, Budi had told her to practice Universal Precautions. Leni delivered at about 7 AM. After the delivery, the midwife received a call from someone who informed her that Leni was HIV-positive. The midwife was startled and became angry. She snapped, ‘Why didn’t [you] tell [me]?’ She left the delivery room without even washing the newborn. At about midday, the midwife returned to ask them to leave, and to settle the costs later. I heard from Nani that the midwife had actually gone to puskesmas Karawang to verify that Leni was HIV-positive. Later, the midwife called Budi and demanded that he replace all the equipment she had used during the delivery – scissors, forceps, underpads, gloves, clothes. He initially refused and said that medical equipment can be sterilized. The midwife insisted by saying that if the situation became known she would lose business. Budi finally agreed and had to reimburse about Rp. 1.2 million (US$ 133).
This case also illustrates the midwife’s lack of knowledge about HIV/AIDS, which I observed among other midwives in Karawang when I attended an HIV/AIDS educational campaign at puskesmas Pasirkaliki in Rawamerta sub-district in September 2006. A village midwife asked two questions to the Pantura Plus speaker, who had just explained the risks of HIV transmission. The first was about when HIV symptoms appear; the second was how one can tell whether a baby is HIV-positive. Similar questions were raised in a meeting of midwives at puskesmas Rawamerta in August 2006; one midwife asked how she could protect herself from her patients. These are basic questions which healthcare providers in general should be able to answer.

Social support

In all parts of the world where the HIV epidemic has taken hold, networks for HIV-positive people have emerged to combat stigma and discrimination at home, in the workplace, at schools, in the health services, and in communities in general. Through the idioms of ‘self-help’ and ‘empowerment’, NGOs have created support groups to encourage the ‘greater involvement of people with HIV/AIDS’ (Vinh-Kim 2005:127-128).

In Indonesia, NGOs – international, national, and local – were the first to establish support groups and organizations for Odha; prominent among them was the Jakarta-based NGO, YPI. After the first case of HIV in a pregnant woman was found in Karawang in 1996, YPI established a village post in the town. In its public campaign for HIV/AIDS prevention, YPI provided VCT services through which it could identify Odha. As many Odha as possible were involved in its meetings, trainings, seminars, workshops, and campaigns. Their growing number over the years informed the creation of the KDS (kelompok dampingan sebaya or peer support group) Pantura Plus in 2004. Registered as a legal entity in 2006, Pantura Plus serves Karawang as well as the districts of Purwakarta and Subang. The group aims to empower Odha to overcome their problems, enhance their involvement in HIV/AIDS control and prevention, create non-discriminatory environments, enhance their access to health services, and uphold their human rights.
As with other support groups, Pantura Plus spreads the message that one can ‘live positively’ with HIV – that the diagnosis does not mean imminent death. Through talking, sharing, and interacting with other Odha, HIV-positive women and men can see new horizons for their lives. The role of support groups is one of the factors informing women’s decisions regarding their sexual and reproductive health.

Arif, a counselor at Pantura Plus, recounted his experience of accompanying Maryam to deliver at RSCM hospital. He saw that Maryam was upset: her husband was not present while the caesarean section was her first experience of surgery. Arif comforted her by chatting and joking. Other women stated in a focus group:

We as Odha [are] sometimes unstable, depressed. [We] need moral support. We can call, share or even complain. If there is [a] counselor, it’s good because there’s someone who’s supporting, taking care of [us]… (Sinta, age 27).

I want to know more about how to take care of my child. YPI knows more about pregnant mothers and children…. Support makes us enthusiastic about life (Yanti, age 28).

Sometimes [a] nurse doesn’t understand us as Odha. It seems they serve us insincerely. When I delivered, I was asked to bring [the] baby’s needs from home… so [my] buddy [from the support group] helped me a lot in this situation (Ani, age 30).

Alongside access to important information, becoming a support group member creates a sense of belonging. HIV-positive individuals gain the opportunity to meet others in the same situation, to talk freely without worries of discrimination.

Euis – an HIV-positive mother of one child and the wife of Rudy, a case manager at Pantura Plus – was recruited in early 2007 as an outreach worker for a program funded by the Finnish Embassy. Her job was to undertake home visits to Odha who were not actively involved in the Pantura Plus program. Despite getting only her transportation costs reimbursed, Euis was happy with her work; it meant she could mingle with other Odha and provide them with support. Once she attended an IPPI national meeting in Surabaya, representing Odha in Karawang. She felt that the support group helped reduce Odha’s sense of isolation. In the support group,
being *Odha* becomes a collective identity to fight against the stigma and discrimination they encounter in society (Liamputtong, Haritavorn & Kiatying-Angsulee 2009:866).

Almost all female *Odha* interviewed in this study were incidentally, partially, or fully engaged in Pantura Plus activities; the NGO has taken the principle of greater involvement of PLWHA to heart. Between 2005 and 2008, its main program focused on harm reduction for IDUs and prisoners, with funding support from ASA-FHI and the National Narcotics Board (BNN). On top of this, Pantura Plus has pursued advocacy work with local government institutions – the local Health Office, the district hospital, KPAD, the penitentiary, and the local police – on access to health services, CD4 testing, ARV treatment, life skills, drug substitution therapy for IDUs, and the commitment to fight HIV/AIDS.

As I discussed in Chapter 3, many *Odha* come from low income families. Most are unemployed. Involvement in HIV/AIDS programs thus provides them with an income, though only enough to subsist. The support group also becomes a place for *Odha* to seek help, both formally and informally. The harm reduction program, for example, employs outreach workers and case managers. An outreach worker receives Rp. 1 million (US$ 112) as an honorarium and Rp. 300,000 (US$ 33) for transportation costs – slightly higher than the district minimum wage of Rp. 854,373 (US$ 95) for formal workers. While these individuals depended on Pantura Plus for their livelihoods, they were also well aware that the harm reduction program was temporary, lasting only so long as ASA-FHI provided funding.

One day in February 2007, Nani, who worked for the HIV prevention and STI screening program for sex workers between May 2006 and June 2007, expressed her anxiety about the future of her position. She asked me whether I had a project that I could involve her in if her contract ended. At that time she did not know whether ASA-FHI would extend the program. In March, after monitoring and evaluation, ASA-FHI agreed to provide another one year grant. Nani told me that she was relieved to hear the news; she felt secure for the near future.
Conclusion

This chapter discussed how HIV-positive women deal with reproductive risks, particularly in pregnancy and delivery. In the resource-poor setting of Karawang, and with little family support, these women have to rely on their social networks – friends, NGOs, and support groups – to access PMTCT services in order to secure safe deliveries and to prevent vertical transmission of HIV to their babies. The PMTCT services offered in urban centers are often prohibitively expensive for low income HIV-positive women. Their options thereby constrained, their decisions reflect the kind of ‘ambivalence coupled with pragmatism’ (Lock and Kaufert 1998:2) characteristic of women’s engagement with the medicalization of reproduction.

We saw that physicians often recommend the post-partum sterilization of HIV-positive women, a practice also seen in other countries such as Thailand and Brazil. Although there was – in theory – consent from patients, their ‘decisions’ were strongly influenced by medical professionals. Nor were patients well informed about sterilization.

In navigating HIV in pregnancy and delivery, the role of NGOs and support groups is crucial, not only for disseminating up-to-date information but also for helping HIV-positive women access PMTCT services. However, the dependence on international funding agencies makes the provision of PMTCT services, even in urban areas, highly uncertain.