Life and death with HIV/AIDS: life stories from Karawang, West Java
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Citation for published version (APA):

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HIV/AIDS is not only an individual illness, but an illness of the family. The presence of HIV/AIDS has different consequences for different families, just as illness progressions differ. I observed that the impact of illness was felt in some families even before the diagnosis of HIV. This affected the lives of couples as well as their extended families.

Nani was a divorcee when, before knowing her seropositive status, she suffered opportunistic infections. Dina did not know that her husband had died of AIDS until she took the required medical test to be an overseas migrant worker, which confirmed her own HIV-positive status. Being the eldest daughters in their families, both Nani and Dina had to provide for their younger siblings by working outside the village.

Gender inequality often puts the wife in a disadvantaged position vis-à-vis the husband. Gender norms prescribe that the husband is the head of the family, whether or not he fulfills the expectations associated with this role. Wives often find it difficult to speak up; they have been taught to obey and keep silent, to uphold family harmony (Sciortino 1999:236-237). As we will see below, being HIV-positive can further disadvantage the position of wives.

Tika, an ex-junkie, talked about her family life with her first husband, who was also a junkie. She came from a middle class family whose fortunes declined after her mother (the main breadwinner) passed away.

After [I] married, I stayed at [my] parents-in-law’s house, though not for long because I was uncomfortable with my husband’s sister. She didn’t like me getting married because her brother was not ready and had no job. I couldn’t stand it, so I finally moved to my house. I felt uneasy with my parents-in-law because she [mother-in-law] was so kind…. Staying at my house, my husband didn’t look for a job, though he promised me that he would. It was a shame to my parents that my husband had no job. But it seemed he had no motivation, only wanting to hang out…. He was kind to me when he wanted to make love. Sometimes I felt reluctant, but a wife must obey her
Tika’s husband, Dadang, preferred hanging out with his friends. Even the birth of their first baby had little effect.

He kept drinking. He promised to look for a job, but what? I was happy with him only for the first five months. He cared, our sexual relationship was very good…. But when he started drinking, I was feeling ill because I was pregnant…. I was stressed because my daily needs were on my mom’s expense. I was ashamed! I often talked to my husband, but he never seemed to understand and had no shame. Though we lived in my house, we were like guests. It sucks! When I was about to deliver, my husband was not around…. I expected he would take care of me, but it was my mom, again, who bothered. I felt so sinful. I was taken to the hospital. My family worried about my baby because the doctor said she gulped my water. My water was green, but finally my baby was safe and healthy after [she was] admitted for seven days. I gave birth in September 2001. My parents-in-law and mine were so happy. But when she was four months, she suddenly fell sick. The doctor said she had acute lung disease. Her chest looked blue. Eventually she died, on 11 January 2002. I was deeply sad. My parents too; she was their first grandchild… I was so stressed, shocked! My first child, who suddenly died.

A month later, Tika’s mother passed away. Tika recounted her sorrow at this time; her mother was a figure who had always loved and protected her.

She passed away before my eyes. I was whispering istigfar⁶⁸ in her ear because she looked so severe. She had kidney failure. She started hemodialysis, but just once…. I wanted to repay my mistakes, always disappointing [her] and making her sad. When she passed away, I felt a deep loss.

Tika now followed Dadang and moved back to her parents-in-law’s house. Dadang’s sister remained unwelcoming. Tika decided to look

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⁶⁸ Istigfar is a chanting prayer that usually addresses a dying Muslim. Generally, istigfar is an expression of remorse for misconduct according to God’s law.
for a job, finally finding work as a garment factory worker. Dadang subsequently found a job as a driver. Confident of a better future, they rented a small house near her workplace. But while Tika saved money for their future, she felt Dadang was being dishonest about his income, which he did not divulge to her. Tika then became pregnant.

When I had been working for four months, I quit because I was pregnant again. My mother-in-law forbade me to work. She worried about my baby. Actually, I seldom made love to my husband…. He didn’t want to use [a] condom, but I also [did] not use contraceptives. I asked him to ejaculate outside, but at last, it happened.

When Tika was about to deliver, Dadang quit his job without clear reason. Her parents-in-law took care of the hospital costs, and she gave birth to a baby girl, Asih. Shortly thereafter, Tika’s health started to deteriorate. One day she noticed that her tongue had white patches and she spoke to Dadang. He said, ‘You know, that’s a symptom [of] people with HIV. Before you used it [injecting drugs], right? That must be HIV’. While she did not believe him, she was afraid. Her four months-old baby girl also suffered from recurrent illnesses.

Tika experienced numerous symptoms, from fever to hemorrhoids to wasting. Suspicious about her worsening condition, her father advised her to go to the hospital. The doctor suggested she do an HIV test, and the result turned out to be positive. Knowing her status, Dadang reacted bluntly: ‘I don’t want to be with you anymore. If I’m infected, I still have five years to have fun. I don’t want to take care of sick people like you’. Dadang’s family – except her mother-in-law – also discriminated against her, forcing Tika to live with her father again. She decided to test her baby; Dadang agreed to test as well. Tika’s daughter Asih was HIV-positive, her husband negative. Shortly thereafter, Dadang came to her house and proposed a divorce, to which Tika agreed. After the divorce, Asih’s condition declined rapidly. After a week in the hospital, she died. Mourning, repentance, and feelings of sin engulfed Tika.

Tika’s married life reveals the difficulties many wives experience communicating with their husbands. Gender inequality in their relationship forced Tika to assume the couple’s economic responsibilities, and she had no autonomy over her reproductive
destiny. Her seropositive status further made her the target of stigma and discrimination from her husband and his family.

As we saw in Chapter 4, Dina became a housewife after she remarried since her new husband Alim prohibited her to work. She had disclosed her HIV status to Alim before they got married, and he had accepted her condition. During a visit to her house in Ciliman village in late January 2007, she looked gloomy and sad. She also appeared thinner than a few months ago. Dina quietly told me that Alim had strictly disallowed her to engage in any activities outside the house. A few months before, Pantura Plus had offered her a place in an ARV treatment advocacy program, which she had to decline. Alim would look for her even when she visited the neighbors. She felt depressed: ‘I’m tired. Tired of many things’. Other aspects of Dina’s behavior suggested a poor marital relationship. For instance, she had a cellular phone that she hid from her husband and only occasionally turned on. I knew that if Nani or I received a text message from her, it meant that Alim was not around. Once she asked me not to let Alim know her mobile number.

Dina and Alim’s relationship seemed even worse when I met Dina at Nani’s place in late March 2007. She had just returned from Cikampek market with Nani. She was planning to join the four-day life skills training for Odha in Bandung; a staff member at PKBI Bandung had invited her. Alim, however, had not given his permission. This made Dina desperate. They had quarreled and it seemed that Alim had hit her; Dina showed Nani the bruise on her back. She now ran away from home and stayed at Nani’s place. After the training she returned to her house, but her marriage was in dire straits.

One day in October 2007 I got a text message from Dina. She told me that she had diarrhea and that she had stopped taking ARVs for three months. When I called her, her voice sounded sad and weak. She was in Sukabumi, a town in southern West Java. She had been away from home for three months because her relationship with Alim had deteriorated. She told me that she was longing for Andre, her son. Several weeks later, I heard from Nani that Dina had returned to her village after Alim left her house to avoid debt collectors.

Dina’s married life illustrates her husband’s authority. She was afraid to openly oppose his wishes, fearing his anger and violence. Alim was the family head and breadwinner, and demanded
Dina’s obedience. Dina could only show her autonomy by running away.

Budi, 29 years old, was an ex-junkie who used to work as a security guard in a Karawang factory. He suffered from diarrhea, thrush, and toxoplasmosis until he was tested for HIV without counseling in early 2004. The result was positive. All the medical costs at the time were charged to the company, but afterwards he was fired due to his HIV status. Unemployed and not yet fully recovered, Budi joined the YPI village post as a volunteer and became an HIV/AIDS activist. He felt fortunate that his wife and four year old son were HIV-negative.

His wife, Neneng, slowly came to understand HIV/AIDS as Budi shared his knowledge from the various trainings. However, his income as a volunteer was uncertain. To meet their daily needs, Neneng opened a small stall in their rented house; later she worked as a shopkeeper in the mall. Budi spoke positively of his marriage. I noticed that Neneng often joined YPI and Pantura Plus trainings, workshops, and campaigns, although only as an observer or volunteer. The first time I met Neneng in 2005, she told me that she wanted to participate in YPI activities to know more about HIV/AIDS.

Budi reported:

Some time ago when I relapsed and drop [felt weak], support from [my] family was good for me to stand up again. Yeah, until now family support is good, particularly my wife who also knows about HIV [because of the information] that I shared.

Sometime after this, however, their marriage went into decline. It started when Budi relapsed and started using drugs again in November 2006. I got the story from Euis. Neneng had told Euis that her bank savings were almost depleted, though she had never withdrawn from them. Her ATM card was only used by her and Budi. Neneng had never imagined that Budi would withdraw money without her consent. She had also assumed that Budi stayed away from drugs. According to Euis, Budi had relapsed heavily and was injecting drugs every day. When I met Budi in late January 2007, I asked about Neneng. He answered briefly, ‘I don’t know. She didn’t come home for several days. I don’t care [if my] wife goes away, I can look for another one’.
Sometime in March, I learned that Budi had just married Leni, an HIV-positive woman from Jakarta. Probably they did *kawin sirri*.\(^6^9\) They rented a room in Nani’s place in Cikampek. Budi and Neneng’s relationship remained unclear as they were not legally divorced. Later, Budi told me that he divorced Neneng verbally, which for him was legitimate under Islamic law.

These vignettes all reveal aspects of the inequality between husbands and wives. As wives, as mothers, and often as breadwinners too, women shoulder most of the family responsibilities. Their HIV status does not affect relationships within the family. Men – whether they are HIV-positive or not – perceive themselves to be the heads of families, regardless of whether they fulfill their socially expected roles.

**Negotiating identity: between silence and disclosure**

Studies in many parts of the world have shown that accusation, stigma, and discrimination are the dominant social responses to HIV and AIDS (Sontag 1989; Farmer 1992). These responses can be considered the primary social problems of the pandemic. Accusation, stigma, and discrimination are also experienced by caregivers, family members, and close friends due to their relationships with *Odha*. Stigma and discrimination must be understood in terms of power relations in society that reflect and reproduce the inequalities of class, gender, age, race, ethnicity, sexuality, and sexual orientation (Paiva et al. 2003; Parker and Aggleton 2003). Gross differentials in power fuel stigma and discrimination, for instance against lower class sex workers. As I discussed in Chapter 3, HIV/AIDS in Indonesia is largely seen as a ‘prostitute’s disease’, one that symbolizes sinfulness, amorality, infidelity, and promiscuity. Hence sex workers are often raided by police who perceive them as a social pathology, or by conservative Islamic groups who see them as destroyers of morality.

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\(^{69}\) *Kawin sirri* literally means ‘secret marriage’. It is a common practice among Indonesian Muslims. Though religiously legitimate, it is not registered at the Religious Affairs Office (KUA), and is usually witnessed by close relatives or friends. *Kawin sirri* is also practiced by men who already have a wife but who do not want to openly practice polygamy. The phenomenon also occurs among university students in Yogyakarta as a way to avoid premarital sex and sin (Nurhaedi 2003).
Fear of stigma and discrimination deter *Odha* from disclosing their seropositive status. In almost all the cases I came across, disclosure was limited to an inner circle of parents or siblings, a spouse or current sexual partner, one’s closest friends, peer group, or support group.

This section examines the problem of disclosure, particularly in the context of the spousal relationship, and how being HIV-positive influences one’s sexual and reproductive practices. My respondents perceived the term *Odha* (i.e. PLWHA in Indonesian) as encapsulating the identity of being an HIV-positive person. Nevertheless, the term is used almost exclusively within the world of HIV/AIDS activism, and is still not widely understood by the general public (Boellstroff 2009:358). How does an *Odha* decide whether, when, what, and to whom to disclose? As we will see, *Odha* employ various strategies to deal with their stigmatized identity.

It depends on us. My neighbors don’t know… I think other people don’t need to know. People are not always accepting of us with this disease. Our child [is] discriminated [against], isolated by people… so don’t let people know (Vera, age 28).

Until now I still keep secrecy, my family doesn’t know. They only know I have lung disease. I also said just lung disease (Nani, age 31).

I don’t want to disclose… until the end of my years. Just me who knows. My family won’t accept it (Yetti, age 30).

I asked Jaya whether his neighbors knew he was HIV-positive. He thought that they might, perhaps from other people. I asked how he knew whether other people knew. Jaya told me that sometimes when he hangs out and drinks with his friends, the head of the RT (neighborhood unit) scolds him: ‘Jaya, you’re already sick, [and] still hanging out. You better go home’. However, he said that he did not feel any stigma or discrimination from his neighbors. Although there were instances of involuntarily disclosure by someone else, most *Odha* in this study avoided voluntarily disclosing their status in their community. In Jaya’s case, he only assumed that his neighbors knew. As an activist, Jaya was perhaps more self-confident than other *Odha*. Still, he did not voluntarily disclose his status.
I asked Firman whether his parents knew his HIV status. He answered, ‘Not yet. When I wanted to test, I only told them that I might have hepatitis. So they only know I did [a] hepatitis test’. When he became more active in Pantura Plus, he often brought home HIV/AIDS brochures and put them on the table in the living room. He expected his parents would read them.

I talked to Jajang’s mother while sitting beside his mattress in the living room. His mother said that Jajang did not want to talk openly about his illness, though she could understand and accept his condition. Sometimes she sought information from his friends in Pantura Plus, but this angered Jajang. His father did not know much about his condition, his mother said.

One strategy for concealing one’s serostatus is to ‘cover’ HIV/AIDS with other illnesses. But such ‘covering’ only works until the illness progresses to reveal the truth. Later during my fieldwork, Firman explained to me that his parents probably knew he was at risk due to his drug use. In addition, his younger brother – also an IDU – suffered severe illness and was bedridden for more than a month until he died of AIDS.

Some Odha who disclosed their HIV status to immediate family members found it less difficult. Jaya talked to me one afternoon at the Pantura Plus office. He recounted that when he decided to go for HIV testing, he already had enough information. He was suffering from opportunistic infections when he took the test, and after receiving the result he immediately told his parents. His father reacted by saying, ‘You have to accept it. That’s the risk’. I asked Jaya how his father could so easily accept his son being an Odha. Jaya said it was probably the media, which carries news about drug use and HIV. Other Odha also experienced few difficulties disclosing to close family members:

Everybody knows. My mom also knows. I’m the youngest. I have an older brother and an older sister. They know (Yuni, age 32).

My family knows. Father, mother, younger brother. Even my niece often reminds me to take medicine…. My sister also supports me (Rudi, age 28).

A few Odha disclosed to their parents-in-law instead of their own parents. Euis told me that her parents-in-law were kind and open to
her because they were already informed about HIV/AIDS; however, she kept silent to her own parents. Tika also felt comfortable with her mother-in-law, who always cared for her.

Disclosing one’s HIV status can disrupt relationships. This is most obviously the case in the intimate relationships of Odha have with lovers, partners, and spouses. In large part, this is because HIV is perceived to affect only those who fall short of the norms of respectable behavior (Korner 2007:146). The fear is to be labeled as ‘promiscuous’ or worse. For example, Randy was a widower whose wife had died of AIDS but wanted to remarry. He had a girlfriend who did not know his HIV status; he was afraid that she would run away if she knew. I asked Firman, one month after he got married, whether he had disclosed to his wife. He replied, ‘Not yet. I’m still confused. [I am] afraid that she will react, “Why didn’t you tell me before?”’. Though she knew he had injected drugs and that he worked as an outreach worker in an HIV/AIDS program, it seemed she had no idea that he could himself be infected.

After learning that he was HIV-positive, Atma, an ex-junkie, needed time to disclose to his wife. He said he was not sure about the test result and told me he wanted to take a second test. Atma also questioned the level of confidentiality at Pantura Plus. At first, only he and the VCT counselor knew; Atma also knew he had the right to choose whether to disclose his HIV status to others or not. But shortly thereafter, everybody active at Pantura Plus knew his serostatus. He commented that it was ‘perhaps because they are my peer group’. Atma eventually disclosed to his wife. She reacted by asking, ‘How about me? Am I infected? Our children?’ Atma tried to explain that he was infected when he was a junkie. He also gave his wife brochures about HIV/AIDS. His wife nevertheless worried because she had previously been addicted to marijuana. She thought any kind of narcotic could transmit HIV.

The story of Tati reveals the difficulties experienced by an HIV-positive woman to identify as an Odha. Tati was an ex-junkie who had passed through hard times in her life – from a happy middle class family to career woman to drug user to street singer. She contracted HIV by sharing needles. She found out after divorcing her first husband, but told no one about it. A divorcee for four years with

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70 I would like to thank Enrico for doing the in-depth interview with Tati.
two children, she met her soul mate, Jodi, and remarried in June 2002. She recounted her feelings when Jodi asked her to marry him.

I was in his mother’s house. We were chatting, and he suddenly said that he wanted to marry me... I was speechless, didn’t know what to say... I was confused because I was thinking only one thing, the fact that he doesn’t know I’m HIV infected. That’s all! But Jodi has told his mother everything about me. Ex-junkie... blah blah... and he said his mother didn’t mind... I only thought, be honest... no... be honest... no... that's it. Finally I decided to strictly keep my secret. I didn’t know what the reason [was] at that time. I just did not want to be honest. If he had to know, not from my lips... I was really scared.

Their honeymoon was the beginning of an agonizing period.

I was so scared at that time. What should I say if I have sex with him? He didn’t know I’m HIV [positive]... I felt so agonized. If I have to be honest, I’m scared... I lied to him. I said that I was ‘getting it’... What should I do? Being honest is impossible. Having sex with him, though the risk was low, I was afraid he would [be] infected. At that time he looked disappointed, but we didn’t quarrel. He understood that’s [my] monthly period... I felt guilty. Not comfortable to keep lying. My life was uneasy at that time.

This story reveals how Tati felt self-stigma as an HIV-positive woman. She feared that her partner would reject her, even though he had accepted her as an ex-junkie, divorcee, and street singer. She felt guilty for lying to her husband, and was afraid of infecting him. Her background as a junkie, which had ruined her family life – she was divorced and abandoned – was the reason she did not disclose her seropositive status. She feared being abandoned again.

Disclosing one’s identity as an Odha always involves interpretation and negotiation in different social contexts. Disclosure must be perceived as a process that requires gradual adjustment on the part of Odha vis-à-vis their spouse/partner, family, peer group, and community. The result of disclosing one’s HIV status remains

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71 ‘Aku bilangnya lagi dapet’. The phrase ‘lagi dapet’ literally means ‘getting’. Women usually use this term when they are menstruating.
uncertain. Some instances led to acceptance and support; others led to stigmatization, rejection, and blame.

Negotiating risk: sexual and reproductive practices

An important discourse in the international AIDS community favors the rights of individuals to ‘just say no’ to routine HIV testing in healthcare settings and, if found positive, to not inform their sexual partner(s) if this can result in personal harm (Dixon-Mueller 2007:285). This discourse is problematic as it disregards the responsibilities within the sexual rights of individuals, and also ignores the rights of sexual partners to be informed of the health risks to which they may be exposed. This section focuses on how Odha negotiate the risks of infection within their sexual and reproductive practices. Fear, shame, and ambiguity are again central to the story.

Atma had two children and did not intend to have more. His wife, Atik, used the contraceptive injection. I asked what would happen if the contraception failed. Atma said that a child is a gift from God, so he would accept it. Since Atik had not yet been tested, I wondered whether they used condoms. He told me:

I use them when having intimate relations. But my wife said it’s uncomfortable. So I use condoms only occasionally. If I feel weak and less healthy I will use a condom. Because I’m worried if the many viruses in my body can infect my wife. I [would] feel sorry if she were infected.

As an outreach worker for sex workers, Atma had attended several training sessions on HIV/AIDS. He knew that the lower the viral load in the body, the lower the risk of HIV transmission. Hence he believed that whenever he felt ‘badan lagi enak’ or that ‘the body [was] in good condition’, he had a low viral load and condoms were unnecessary. When I asked about the rash on his arms and legs, he said it was an itchy skin disease that was not caused by HIV. Atma was in partial denial. In March 2007, he did a CD4 test and the result was 75. But he still refused to take ARVs when the doctor prescribed them.
I interviewed Firman for the first time in late August 2006. He had found out that he was HIV positive in January of that year. Firman had a girlfriend whose parents were encouraging him to marry. But he was hesitant due to his seropositive status. As he did with his own parents, he started to indirectly ‘disclose’ to his girlfriend by telling her of his past as a junkie and giving her leaflets about HIV/AIDS and drug use. He expected that she would realize the risks of infection, but it seems this was not the case. As I talked to him, it became clear that he intended to marry her without disclosing. In late December 2006, Firman married Tanti in a modest wedding ceremony. Before the marriage, he told me that he would delay having children and would not mind using condoms. When I inquired about Tanti at the end of January 2007, Firman said that she was already two weeks pregnant. Was the pregnancy planned? ‘No actually. I was thinking that if [it was] only the first time having sex [she] would not get pregnant’, he said a bit shyly. I asked him why he did not use a condom at that time. ‘I don’t know. I’m so happy that finally I got married. I just didn’t think about the risk that time. Maybe I’m so glad’. He added that his condom use was inconsistent, but that ‘I am also often coming outside’. So he practiced coitus interruptus. For the time being, Firman said, he was not having intimate relations with his wife due to her pregnancy.

Firman’s case shows us that emotions – feelings of happiness, intimacy, and love – intertwine with reproductive beliefs and influence sexual practices. Firman’s belief that having sex for the first time does not lead to pregnancy is common among adolescents in Indonesia. Lack of sexual and reproductive knowledge is still the norm among young people.

As I recounted in Chapter 4, Nani delivered her first baby in 1995, which then died after seventeen days. Towards the end of my research period, at the age of thirty-one, she wanted to have another child. After marrying Rusdi, she used the injection contraceptive but it was ‘gak cocok’ (literally meaning ‘not a match’) because it made her bleed. She stopped using it and did not replace it with other contraceptives. Nani told me several times that to be pregnant she had to have a high CD4 count. The last time she did a CD4 test was in 2005.
I really, really want to have [a] child because my only child died… If we want to have [a] child the CD4 is important… I’m confused.

She also had irregular periods, which made her anxious about whether she was pregnant. Nani shared her feelings with me:

Once Gumilar [her friend] asked me, ‘What happened with you?’ I said, ‘I’m stressed. May I share with you?… Honestly, I didn’t get [my] menstruation since the fasting month’. ‘Maybe you’re pregnant’, Gumilar said. ‘You don’t use condoms?’ he asked. I said to him, ‘Honestly, I want to have a child’.

The point of her answer was that she wanted a child. She did not reply directly to Gumilar’s question, though she did reveal that she was not routinely using condoms, despite knowing that this placed Rusdi at risk. Nani did not disclose her HIV status when she married Rusdi. She was afraid that it would jeopardize their relationship. A few months later, she decided to disclose for she felt Rusdi would understand her condition.

First, mas⁷² Rusdi was startled. But he didn’t have any idea what HIV is all about. I tried to explain it. HIV is like this and this… He then tried to understand and said he can accept me as I am. I felt relieved. Slowly I also encouraged him to take the test.

I noticed that Rusdi was supportive of Nani when he came to an Odha gathering night held by KPAD Karawang. It was the first time for him to attend such an event. He told me that he did not know much about HIV/AIDS and mostly received his information from Nani. I asked about Nani’s desire to have children. Rusdi said that he had told her to consult a doctor. He did not mind having another child though he already had one with his first wife. He also agreed to undergo HIV testing if it was for free.

In mid-March 2007, I received a text message from Rusdi informing me that Nani was pregnant. I called Nani on Rusdi’s mobile and asked her how she knew she was pregnant. She had

⁷² Mas is a Javanese term of address for elder brother. A wife can call her husband ‘mas’ if he is older than her.
used a pregnancy test kit available in any pharmacy. Nani said she was confused and had been crying. She really wanted to have a child, as her first baby had died. She asked me what she should do, and what about the ARVs. I suggested she go see a doctor at puskesmas Karawang, to confirm that she was pregnant. On 12 April 2007, I called Nani to just say hello. Dina answered. She was at RSUD Karawang, taking Nani to see a doctor because she had miscarried. When I arrived, I saw Nani sitting in the corner of the waiting room. She was with Budi, Dina, and a young woman whom I later knew as Nani’s contact person in her outreach work. They were waiting for the paperwork before proceeding to the maternity ward. Nani sat with her legs stretched out on the bench. She looked pale, gloomy, and weak. I asked her what she had experienced. She told me that the hemorrhaging had started on Monday night, two days earlier. On Tuesday she only rested in her room, but the bleeding continued. Gumilar had then advised her to go to the hospital.

Unlike Firman, Nani finally disclosed her seropositive status to her husband after they got married. Her desire to have children was her main reason to do so. By disclosing, Nani fulfilled her personal responsibility to protect (in so far as was possible) her partner’s health and well being.

Tati’s case also shows how she negotiated risk with her husband, who did not know that she had HIV. Tati realized that she could not keep lying to Jodi. One day after her period was over, Jodi wanted to make love. Tati recounted:

Finally I made love to my husband. Yeah, I couldn’t refuse. What other reason could I give? Anyhow, it’s my obligation as his wife to accept his request. I tried to offer him [a] condom, but he didn’t want it because he wanted to have [a] child from [me] soon.... I couldn’t enjoy it that time. I was pretending that I enjoyed it.... Actually I was stressed because [I was] afraid he would be infected. Every day was restless...

After this encounter, Tati often refused to make love to her husband, giving various reasons – feeling tired, sick, or wanting to go to sleep early.

I refused, not only [because I was] afraid he would get infected but because I didn’t plan to have [a] child from him.
I was afraid the child would get infected too! ... My other kids still did not know about their fate [i.e. HIV status].... Because I was afraid, I used contraceptives but he didn’t know it. He didn’t want to use condoms when we made love.

One day Tati felt nauseous, which she thought could only be 'masuk angin'. She took medicines but the nausea continued. Fearing that she was pregnant, she and Jodi went to a doctor. Although the pregnancy, which the doctor confirmed, was unexpected, she also felt happy despite her fears. Jodi was very happy for he would have his first child. She delivered the baby boy through caesarian surgery. Tati was elated when she saw her chubby baby and Jodi being so caring; he did everything for them. But fear, anxiety, and guilt eventually returned as she worried about her baby’s HIV status. She decided that she needed more information. A doctor then informed her about an AIDS organization in the Dharmais hospital in Jakarta, which she joined.

What made me worried was when I found out that breastfeeding can transmit HIV and the risk was quite high. I breastfed Miki since he was born till about five months, when I received this information. Scary, right? So I stopped breastfeeding. I replaced it with formula milk. I told my husband that my breasts were painful if [I] breastfed.

Encouraged by the counselor, Tati decided to do an HIV test for her three children without Jodi knowing. She recounted how restless she was while waiting for the results. She prayed and begged for a miracle. All of her children were HIV-negative. She said it was an indescribable feeling; her burden lifted.

Tati’s sexual life declined post delivery for she had no desire. She made love only when Jodi initiated it, without using condoms. Early in 2004, Tati fell sick with acute pneumonia and was hospitalized for almost four months. One day the doctor told her that she was HIV-positive. She pretended to be shocked. When the

73 *Masuk angin* literally means 'wind enters the body'. It is a local term to describe certain symptoms like nausea, dizziness, or gas in the stomach due to decreasing stamina.
doctor asked for her consent to disclose to her husband, she agreed. It was a chance to let Jodi know her HIV status through somebody else.

When he was informed, he [was] stunned. But afterwards he gave me spirit, [he] hugged me. I told him if he wanted to leave me, I was sincere… But he said that he would never leave me…. He also told his mother… and she reacted similarly to Jodi. Lucky me, right? … I just told them, don’t tell my family. Let it [be my] secret life, and till now my family doesn’t know.

Tati’s case reveals powerful gender norms to be a good woman, a docile wife, and a dutiful mother. Her history as a junkie – leading to her being divorced and abandoned – was a bitter one that made Tati extremely secretive about her identity as an *Odha*. Her perception of HIV/AIDS as a stigmatized disease further encouraged secrecy, which made her life restless and unhappy.

Negotiating the risk of infection takes on a different dynamic when both partners are HIV-positive. Tika was divorced by her husband Dadang when he found out she was HIV-positive. After the death of her baby girl, she stopped taking ARVs and her health rapidly declined. She was hospitalized for two months and was wasting away when suddenly her condition started to improve. This happened after two *Odha* from the hospital support group visited her, encouraging her to keep up her spirits. When she returned home, they kept visiting her three times a week. One of them, Johan, was handsome and very kind. She joined the support group and became a volunteer like Johan. Their relationship grew closer, Tika taking the lead. Johan told me:

> I was shocked when she told me that she liked me because I never realized that she liked [me]. I was confused. I’m a shy guy. Never close to girls, let alone [a] girl who tells first…

Johan accepted her as his sweetheart and their relationship grew stronger. One day they made love for the first time. Tika shared her story:
The first time I made love to him, it was in [a] warehouse! Hee... hee... I was so horny. When I asked him, he refused because he [had] never ML [made love], so he was shy. I said I will teach you. Because it was in a hurry, I didn't use [a] condom, I didn't have [one]. He was afraid to ML because of it. [It's] funny, he was ‘coming’ so fast... hee... hee... I was worried, his ‘coming’ inside [me], it could make a baby.

After this, they made love frequently, Tika always the initiator. Johan admitted that he learned a lot from Tika. Since both were Odha, Johan always wanted to use condoms. Both tried to communicate openly about sex. Tika said:

Johan wanted us to use condoms when ML, to avoid exchange of the virus. Actually, I rather dislike using condoms because [I feel] less pleasure. Besides, afterwards it feels dry, don’t know why... sometimes pain in [my] vagina.

Panic engulfed Tika when she realized she was pregnant. She thought about having an abortion, but Johan was against it. She was still traumatized by the loss of her previous children, and was afraid that she would not be able to marry Johan because of their different religions: she was Muslim, he was Catholic. After intense discussion, they decided to inform their families about their plan to get married. Johan said to me:

I [was] shocked when she said she was pregnant. Huh, I was confused! I thought [we] played safe. But it’s destiny, what can you say? She wanted [an] abortion, but it’s crazy! So I forbade her. But if we wanted to marry, I have [a] different religion.... But I think I’m selfish if [I] only think about religion while she is carrying my child.... So we talked to our families. They agreed. Finally we got married in August.

They married *kawin sirri* and Johan kept his faith as a Catholic. After marrying, they lived in Tika’s house together with her father. During the pregnancy their sexual life was good, though less frequent. They consistently used condoms to protect the fetus.
Religion played an important role in the reproductive decisions of Tika and Johan. A pregnancy out of wedlock is considered a sin in both Islam and Catholicism. Tika’s immediate response was to have an abortion, allowed in Islam up to four months after conception (Anshor et al. 2002: vii). She feared passing HIV to the child, as had happened with her late child. In Catholicism, abortion is prohibited; Johan perceived the child as destiny. Getting married was therefore a way to conform to socially accepted behavior.

**Conclusion**

This chapter has discussed the dynamics of the spousal relationship among HIV discordant and concordant couples, particularly when negotiating the risks of transmitting the HIV virus. In a society where HIV/AIDS is highly stigmatized, silence and secrecy are common strategies for *Odha* to circumvent rejection and discrimination. Disclosure is a social process; its effects are often hard to predict. But as we saw in Chapter 5, many of my informants found that disclosure to their families was met by more acceptance and support than they had initially expected.