Chapter 4

Becoming Infected

Human bodies are ‘carriers’ not only of pathogens but also of stories that explain our lives (Epstein 1995:19).

This chapter presents the lives of four Odha to show what it means to live with HIV on a daily basis. Individually, their narratives underlie ‘the ways we construct the so-called normal and aberrant, and the ways we explain disjunctions between the two’ (Epstein 1995:19). The experiences of the human body with HIV/AIDS are seen as social aberrations; the lives of many Odha have been shattered by the accompanying stories, as well as by physical difference and illness. In the family context, HIV/AIDS challenges ‘normal’ family functioning. These accounts illustrate how self-stigma and silence have limited the ability of Odha to receive the family support and care they need.

Dina’s story

Dina is an ordinary housewife who was probably infected with HIV by her late husband. I met her for the first time at a YPI Karawang workshop in May 2005. At the time, Dina was an outreach worker who made home visits to other Odha. She was a cheerful and easy-going girl, always dressed in pants or jeans, long sleeve t-shirts, and a head cover (kerudung) worn by Muslim women. She was 27 years old at the time of this study.

Dina was born and grew up in a peasant family in the eastern neighboring district of Subang, the eldest of two siblings. Her parents divorced when she was 7 years old, after which she stayed with her mother in Ciliman village, where her mother remarried. From her step-father, Dina has a step-brother and a step-sister. She only finished primary school though her step-brother managed to finish high school. Her step-father and mother were landless agricultural
laborers; in the harvest season they worked anywhere in the Pantura region. During the fallow period, her step-father worked as a construction worker in the city, an off-farm occupation for many rural landless men. But in the last few years, Dina’s mother was often ill. Dina had therefore stopped working in the rice fields.

I visited Dina’s house for the first time in late September 2006. From Karawang town, it took Nani – my other informant – and I about two hours to reach her village by public transportation. Dina lived in an old bamboo-walled house in Ciliman village. Flower-motif plastic tile covered its dirt floor. The house had three bedrooms on the left side, a living room, and a kitchen on the right side at the back. The living room had no furniture except for a single wooden cabinet housing a TV, audio tape recorder, and VCD player. The cabinet was also the partition between the living room and dining room. Her brother and sister used the first bedroom, her parents used the middle bedroom, and Dina, her husband, and her son used the third bedroom.

Dina remembered her childhood as being an ordinary life in a village. She went to public school in the morning and attended madrasah (Islamic school) in the afternoon. In between she helped her mother with domestic chores, looked after her little brother, or played with her friends in the village. When her parents divorced, her father went back to his own village in Sukabumi. Dina remembered that her grandmother, who lived next door, helped to take care of her little sister and often cooked for the whole family. She finished primary school at the age of thirteen and did not continue to junior high school due to economic reasons. Although her mother remarried, the income of an agricultural laborer could not keep up with the increasing cost of basic daily needs. Her mother often had to borrow money from the stall owner when they were in need of basic necessities such as sugar, cooking oil, or gasoline.

Although we keep some chicken in our home garden, we do not consume these. Instead we sell them, because my [step] brother needs more funds to study at school. Especially during the crisis, not only the price of food and other basic necessities increased. School fees did too.
Despite living a subsistence lifestyle, Dina recalled her childhood and teenage years as being happier than her present life. She was a happy child. As far as she could remember, there were no bad memories. Or only one that she remembered clearly, which was when her parents divorced, and her mother cried and was sad for some time. Dina was upset and hated her father, who left for another woman. As she grew up, her hatred faded. Her father, who lived in Sukabumi, only occasionally contacted her, asking about her condition.

When she reached adolescence, her parents demanded that she support the family income, as other young girls did in the village. Many of her friends left the village to look for work. She finally went to Jakarta with some friends. Dina first worked as a domestic worker. After a year, she changed jobs to be a shop keeper in a grocery store owned by a Chinese family. She worked there for more than a year and went home only on *Idul Fitri*, the day after the Ramadan month. Dina was cheerful and nice to everybody, which probably attracted the nephew of the store owner, who also worked in the grocery. He was almost ten years older than Dina, and she called him Ko Afung (‘*ko*’ is from the word ‘*koko*’ which means older brother). They fell in love and decided to get married in mid-1999. Dina resigned from her job and became a housewife. Although she rarely visited her parents, every month she sent some money to them. When she became pregnant in early 2000, Ko Afung fell sick. Their son, Andre, was born in November 2000 when Ko Afung could no longer work.

In 2001, she could not remember which month, Dina submitted an application to a labor company in Jakarta to be a TKW, or overseas migrant worker in the Middle East. She knew neighbors in Ciliman who had enjoyed success as TKWs and wanted to follow in their footsteps. She had to get a job since her husband was severely ill. As one of the requirements, Dina had to undergo a medical check-up, including an HIV test.

I went to PT Amri [a labor company] to do blood and urine tests. Then I waited for the result. My name was called and I was happy because I thought I had passed [the test]. But when I was inside, the doctor asked, ‘What is your work?’ I was confused because I had no work. The doctor suggested taking blood one more time. Then I waited for two hours. That was Friday, because there was Friday...
prayer till 1:00 pm. The result was HIV-positive…. I was sad because I’m a housewife and can get it, HIV infected. I was afraid that [there is] no medicine for HIV… I will die.

Her application was declined due to the medical test result, and she received no further information on HIV/AIDS from the labor company. She went home feeling gloomy. But gradually, she stopped thinking about her HIV status. Taking care of her severely ill husband and the baby boy made her life hard. For their daily needs, her husband’s family supported them. Yet, a few months later, her husband passed away.

Shortly afterwards, Dina decided to return to her parents in Ciliman village as she felt more comfortable there. She actually did not want to depend on her parents, but Andre, her son, was still too small to be trusted with someone else. Fortunately, her husband’s brother sent money every month to meet Andre’s needs. She did almost all the domestic work at home, but kept thinking about working to support her family, particularly her brother and sister who were still in school. Dina said in a focus group discussion among female Odha:

Maybe in the family the burden falls on me, because I’m the first child. And I have to make a living for the whole family, also helped by my husband’s relatives in Jakarta.

Dina began looking for work, asking friends, neighbors, and family members for leads. She realized that with little education and no skills, it would not be easy. Many of her friends and neighbors were looking for jobs in the city or abroad. A girlfriend then offered her a job as a waitress in a restaurant in Karawang. When she got there, her friend told her the truth. The job was as a freelance sex worker near a brothel.

I got that job from my friend… and at first I was so embarrassed and shocked… but what can I say? Life demands it…. After a month or two… I’m getting used to it. I realized that living a life like this… the money we earn… easy goes...

Dina shared a room with her friend and each month she managed to go home to see Andre and give money to her mother and younger
brother. From her friend, she learned how to look for clients and tactics to attract them. She was mobile between Karawang and Purwakarta, and often looked for clients in the hotels rather than on the streets.

Dina was in Karawang when she started to fall sick. She recalled it was about seven months after she began working as a freelance sex worker. Dina told me that she experienced continuous diarrhea for two months, which worsened when lesions started to appear, which then developed into skin peeling – later diagnosed as Stevens Johnson syndrome. She remembered that she felt like dying, due to the indescribable pain. Nani, our mutual friend and another of my informants, told me that Dina’s family and neighbors in the village feared that she would die. Dina recounted her experience:

I was hospitalized five times. The first hospital was Sari Husada Cikampek. Three times I was confined because of continuous diarrhea, for about one year. Once was in the puskesmas. The last one was Hasan Sadikin hospital, because I took the wrong medicine, Bintang Tujuh, four times. It’s overdose. Before I was already injected by a paramedic…. My condition was getting worse, my skin [on my] face [looked] like [it was] burned…. In Hasan Sadikin, [I faced] a lot of discrimination…

Her CD4 count was only thirteen. The hospital then referred her to PKBI (Perkumpulan Keluarga Berencana Indonesia or Indonesian Planned Parenthood Association) Bandung. Afterwards, she went home to Ciliman, though she was still suffering from diarrhea. However, a PKBI health worker visited her every two weeks. She recovered in two months and started ARV therapy right away. In addition Dina took a supplement pill, ‘Wheatgrass’ – made in Malaysia under the license of Nulife, a US-based company – that she received from her brother-in-law. Dina felt that the supplement enhanced her appetite and she seldom fell sick, so she kept taking it.

First, ARV was very hard to get. [I] had to go to Pokdisus at RSCM. The difficulty was between medicine costs and milk for my child…. So I had to choose: getting money for medicines or for milk. Thank God, there are people who want to help me. Until now he (her brother-in-law) still helps me. At that time I bought medicine that cost about Rp.

47 Bintang Tujuh (Seven Stars) is a brand of jamu or traditional herbal medicine.
400,000 [US$ 45] in RSCM. After several months, I began [to] actively involve [myself] in [AIDS] public education. I asked for free treatment and I got it. Only registration fee is expensive, about Rp. 35,000 (US$ 4). In addition, the cost from house to hospital, how much? I take medicines in Bandung.

Since 2005, Dina and other *Odha* do not have to go to Bandung or Jakarta to get ARV medicines. YPI and Pantura Plus now bring the ARVs each month. The ARVs are free and Dina only has to pay Rp. 15,000 (US$ 1.60) to travel to Pantura Plus. But according to Dina, there was something lacking in the ARV therapy procedure. When she had taken ARVs in the hospital in Bandung, she was examined by a doctor, who asked if she had complaints or symptoms. The doctor recorded the complaints and prescribed ARVs and other medicines as necessary. In Pantura Plus there was no doctor; *Odha* could simply pick up the ARVs when needed. They only had to fill in an adherence form which, in her opinion, was useless because there was no monitoring program.

Dina admitted that ARVs had saved her life. She had never thought that she would recover, gain weight, and even look chubbier than before. The side-effects that she experienced most were nausea and headaches. Even after two years of therapy, the nausea sometimes returned. I asked her if she ever grew tired of taking ARVs each day. She was sometimes late to take the medicines, though she knew that if this happened too often it could cause resistance. She also told me that if the ARVs are not *cocok* anymore, symptoms would reappear. *Cocok* means two entities fitting or being suitable for each other, a common expression among Indonesians to explain whether a treatment is effective or not. You may not *cocok* with Dr. X, but *cocok* with Dr. Y.

Dina felt that the HIV in her body made her vulnerable. When she experienced dizziness, cough, fever, stomach ache, or other common illnesses, she often thought that it was caused by HIV. Dina tried to avoid stress and fatigue in her life. She did not regularly test her CD4 count due to the cost. In her last test, her CD4 count was 284. She remembered a doctor explaining that if she wanted to have a child, her CD4 must reach 500.

After her contract as a volunteer at YPI ended in late 2005, Dina went to Jakarta to look for another job. With the help of relatives, she found work in a small cellular phone shop in Cibubur.
She then met Alim, a widower who owned some small businesses. After about six months they got married. Dina became a housewife again for her husband prohibited her to work, even though she wanted to. Alim, a widower with three children, had a very different background from Dina. He was born to a Betawi\textsuperscript{48} family in Jakarta and grew up there, was a university graduate, and liked to do business. All his children lived with his ex-wife. He seemed to be a devout Muslim and well off. He had a small cellular phone shop in the outskirts of Jakarta as well as some reflexology massage outlets. After their marriage, he gradually moved into Dina’s house and planned to plant \textit{jarak} trees in a 500 square meter rented lot just across from Dina’s house.

When I visited Nani in Karawang hospital in mid-April 2007, I met Dina, who was no longer wearing a head cover. She appeared cheerful, smiling. I did not ask her about Alim. A few days later, Nani told me that Dina had decided to run away from her husband and was staying with a girlfriend in Cikampek. After attended a training session in Bandung, she quarreled with him again and felt she could not stand it anymore. I later lost contact with Dina when she changed her mobile phone number. Nani did not know her whereabouts, though Dina would occasionally drop by at Pantura Plus or at Nani’s rented room. One day in November 2007, Nani told me that she had met Dina somewhere in Karawang. She seemed to have returned to sex work.

Dina’s story reveals a woman struggling to survive after the death of her husband, herself suffering from AIDS. She found out that she was HIV-positive without having any idea about the disease. Like a drifter, as her friends said, Dina continued her life without much support from her family.

**Nani’s story**

When I first met Nani, she was a childless 29 year old divorcee who had been married several times in the course of her life. I first met her in April 2005 at YPI Karawang office, when she participated in a focus group discussion for PLWHA. She looked rather small.

\textsuperscript{48} Betawi is the indigenous ethnic group of Jakarta.
compared to the other female participants. She was about 5 feet 2 inches tall, slender, and had a tan complexion and hair down to her shoulders. Nani is a Sundanese from Cianjur, a district in the southwest of Karawang. She moved to Karawang in early 2004 when she joined an HIV/AIDS prevention program run by YPI. In the focus group, she told us about the time when she found out that she was HIV-positive:

I found out [I was] positive in 2002. In the beginning I didn’t know. Every night I felt continuous fever until one week, two weeks, one month…. I just stayed at home until I heard on radio Pasundan that there is a clinic on Soekarno-Hatta Street.49 I wanted to know what illness I have. [I was] treated with medicines by the doctor but [I] didn’t recover…. In the hospital the doctor asked me to do a test. I don’t know what kind of test…. Its result was I’m positive… I [was] confused about what [the] disease was and about my life afterwards….

Nani was born in 1975 and grew up in a peasant family in Cianjur Wetan. She had one elder and two younger brothers. Her elder brother was married and lived in Cianjur as an agricultural laborer. One younger brother had stayed and worked in Bandung as a shop keeper. The youngest brother had stayed with their parents in the village. She had attended both public school and madrasah. She stopped her schooling after finishing primary school and helped her parents with domestic work. Her parents then arranged for her to marry when she was thirteen years old. Nani told me that she did not understand what marriage was because she was too young. She remembered that on the wedding day she kept playing with her friends in the backyard. Her husband was a bit older than her. Although she and her husband shared the bed, there was no intimate sexual relationship. She felt her husband a stranger. Less than a year later, they divorced.

The following year, her parents arranged a second marriage for her. As with the first one, Nani did not care much about this marriage. I asked why her parents wanted her to marry. She said because of community tradition and perhaps to lighten their burden of raising children. Her family only had a small rice field for their subsistence. In this second marriage, she again had no intimate

49 The street is located in Bandung, the capital city of West Java province.
sexual relations with her husband; she felt too young and felt no emotional connection to him. Nani told me that she did not even remember the events of her two marriages. She divorced for a second time.

When she was eighteen years old, her parents encouraged her to marry again. She finally married for the third time, with a man from a neighboring village. This time she got pregnant and delivered a baby girl in 1995. Sadly, however, the baby died within 17 days. Nani recounted that her baby was tiny, less than two kilos. Probably its low birth weight was one of the reasons her baby did not survive. Afterwards, her marital life was in jeopardy. It ended with divorce.

Nani decided to look for a job to help her family’s finances. With the help of her neighbor she went to Bogor – a town south of Jakarta – to work as a domestic helper. Her salary was Rp. 50,000 (US$ 22) per month. She sent some money home to her mother, though not every month. After almost two years she quit the job with the expectation of finding a better one. A friend in Cianjur Wetan persuaded her to look for a job overseas. She followed her friend’s advice and went to Jakarta to submit an application to an overseas labor company. Her parents had to borrow money from a neighbor to pay for her passport, medical check-up, agent fees, etc. Nani stayed for about four months in the company’s shelter before she departed to Riyadh, Saudi Arabia, in early 1998. Over lunch in a food stall, she recounted:

I worked in a family with nine children. I didn’t imagine it before. I was so tired working there. No time to rest! I couldn’t take care of nine children. Only seven months then I asked to go home. I was thin at that time. The cost to go home was [paid for] by me. Fortunately, my employer gave me my salary. But it was for the travel costs, the agent, and a little to pay my debts. So I went home with nothing.

Afterwards, Nani stayed at home for a few months. She decided to go to Jakarta and worked with an employer who sold fruits in Chinatown. After about one year in the capital city, Nani married a Sundanese man from Garut. He was a vegetable seller. One day she went home to Cianjur Wetan because her father was sick and she had decided to take care of him. When her husband came to the village and stayed for a couple of weeks, Nani realized that, ‘He was
a drinker and [had a] temper. He quarreled with a neighbor and almost wanted to kill him. Therefore I finally asked for divorce’.

After this fourth divorce, she stayed in the village to help her mother and brother cultivating the rice field. Less than a year later, Nani met a man from Sukabumi in Cianjur town, a street vendor. A few months later they married in her village. But her husband did not always stay at her house because of his work. He went back and forth between Cianjur and Sukabumi. Their marriage lasted about six months and ended in divorce.

Nani now felt that she had to look for a job in the city to get a higher income. Coincidentally, a female friend invited her to come and work in a restaurant in Bandung. Nani was interested and decided to accept the offer. Once in Bandung, she realized that her friend actually worked in a brothel. Though feeling deceived and reluctant, she began to work as a sex worker in a lokalisasi. She recounted her first experience with a client. She was scared, trembling, and disgusted. She closed her eyes tight and did not think she could do it. For one long week she was in shock and her heart beat rapidly whenever a client approached her. A few months passed and she grew accustomed to serving clients without being frightened.

After about six months, Nani went home to look at her mother who had gotten sick. She then met a man from her village who worked in Pontianak, West Kalimantan. A few months later they got married, just before her husband left for Pontianak. Nani stayed to take care of her mother and waited for her husband to return. One day her husband called from Pontianak to say that he was suffering from liver disease and could not return soon. Economic pressure to meet daily needs forced Nani to return to the lokalisasi in Bandung. It was December 2002 when she started to fall sick, as she described in the focus group. Recurring fever and no effective treatment brought her to a clinic, which she later knew was PKBI Bandung. She was referred to Hasan Sadikin public hospital for HIV testing and eventually found out that she was positive. Her condition worsened as she suffered from herpes. When she decided that it would be better to go home, a PKBI staff member accompanied her to Cianjur Wetan.

I was taken home by PKBI. For two months I could not get up, just laid down. In the village I went to a paramedic
twice, but [was] not injected because of high fever. I only got paracetamol and ointment. They [PKBI] came from Bandung when my family called to inform [about] my condition. For one year I only stayed at home. Nothing to do, [I was] stressed… desperate.

Her husband refused to return to Cianjur. Nani proposed a divorce.

Being an HIV-positive woman led Nani to a different path in life. Afraid of stigma, she did not disclose her seropositive status to her family. After almost a year in the village, PKBI staff invited her to participate in the HIV/AIDS training for Odha in Bandung, where she met Dina for the first time. For almost three months, both lived in the PKBI shelter, learning about HIV/AIDS and volunteering with PKBI activities. Nani was assigned to a telecommunications stall. She often mentioned Ibu Nunik (‘ibu’ literally means ‘mother’), a PKBI paramedic, who was attentive to her and Dina.

In mid 2004 she began ARV therapy, provided by PKBI staff. Ibu Nunik gave her a great deal of information about ARV medicines, which affected her decision to start this lifelong therapy.

First time taking ARV medicine, there were side effects… nausea and dizziness. It’s like no appetite, [I] wanted to throw up. After a few days, it’s normal again. The worst effect of Duvi Nevi\textsuperscript{50} was migraine. Even now it’s not gone…

The side effects were initially frustrating and she even considered stopping the medication. Slowly she became accustomed to the therapy, particularly when she grew more involved in the HIV prevention program.

In one of the trainings she attended in Bandung, Nani met Budi, a volunteer at YPI Karawang. Budi invited her and Dina to join the YPI program in Karawang. She was interested and participated in the training. By mid-2004, Dina and Nani were working as volunteers and staying in a room at the YPI Karawang office. Their job was to go on regular home visits to Odha living in the villages surrounding Karawang. To do so, they rode a motorbike. Nani enjoyed her activities without fear of stigma and discrimination; her colleagues had a good understanding of HIV/AIDS.

\textsuperscript{50} Duvi is the short term for Duviral (lamivudine + zidovudine); Nevi is for Neviral or nevirapine.
During her voluntary work at YPI, she met Rusdi, a company bus driver. Every two weeks or more, Nani visited Dina’s house in Ciliman village. To save on transportation costs, Nani and Dina usually hitchhiked in one of the company buses bound for Cikampek, transferring there to a public minibus headed for Ciliman. Rusdi served the Bekasi-Cikampek route in the morning and afternoon. Nani fell in love with him, even though Rusdi had a wife and children. She described him as mature, tender, and patient. They decided to get married in April 2006, with permission from Rusdi’s first wife.

The HIV/AIDS program ended after one year. Nani now stayed at Cianjur Wetan or at Rusdi’s house in Purwakarta. A few months later, a colleague from YPI called and asked her to come back to Karawang. She was offered a place in a new HIV/AIDS prevention program – funded by Family Health International – as an outreach worker for sex workers. Nani told me that she was happy and immediately accepted the offer. She then rented a room in Cikampek since it would be easier for Rusdi to stay with her, although not every day.

In mid-March 2007, I received a text message from Rusdi informing me that Nani was pregnant. I called her and suggested that she see a doctor at puskesmas Karawang to check on her pregnancy. In early April 2007, after two days of hemorrhaging, Nani miscarried. She was hospitalized for a night and the doctor advised her not to get pregnant for some time. For about a month she tried to reduce her activity, and in June became pregnant again. At the end of September 2007, she had a CD4 test with support from Dinkes Karawang. The result was similar to her previous test, 274. Nani grew worried about whether the ARV therapy was working properly. She told me that the result made her restless and she found it hard to sleep. She was anxious because of her pregnancy too. Despite her anxiety, the pregnancy was in good condition and she had no complaints or medical problems. She routinely visited doctors and midwives in the puskesmas. Nani knew that a higher CD4 count would be better to reduce the risk of transmission to the baby. She told me that she wanted to see Professor Samsuridjal, a prominent doctor and famous figure in HIV/AIDS activism since the beginning of the epidemic.

One Saturday morning in early November 2007, I accompanied her to see Professor Samsuridjal at Dharmais hospital. After getting her weight and blood pressure checked, we waited for
about 30 minutes until her name was called. Nani had consulted with Professor Samsuridjal about three years before, when she had her first CD4 test. The doctor asked what her complaint was. Nani told him that she was five months pregnant and wanted to know what to do next. He pointed to the examination bed and asked her to lie down. I did not see what the doctor did, but the examination took less than 30 seconds. He then asked for her latest CD4 count, which was 274. Professor Samsuridjal said she had to check her viral load, since it would give a better picture than a CD4 count alone. He called a nurse and told her to inform Nani about whether a free viral load test was available at RSCM hospital. He wrote a referral letter to Pokdisus RSCM to prepare PMTCT services for Nani. Some vitamins were also prescribed. On the way to the cashier, Nani looked relieved.

In February 2008, Nani underwent a cesarean section at RSCM hospital. After a month in Cikampek, her baby boy was taken to be raised by her sister in her village in Cianjur. Nani finished her contract at Klinik Kita in July 2008 and returned to her village. Once in a while I called her or sent an SMS to say hello. She was happy to know that her son was HIV-negative. Then unexpectedly, in November 2010, I received an SMS from Rusdi, her husband. He told me that Nani had been severely ill for the last three months, after stopping her ARV therapy. I was startled to hear this; I knew that Nani had previously adhered to treatment. A few days later, sad news came from Rusdi. Nani had passed away in her house.

Nani’s life story illustrates how one woman became vulnerable to HIV infection. She never found out how she was infected. It also shows how cultural norms that increase risk can be imposed on individuals. The frequent marriages in Nani’s life must be seen as such a risk factor.

**Tika’s story**

This is the story of a female injecting drug user who has surfed the wave of life upside down. I knew her through a friend who worked in an NGO in Jakarta. Tika was born in September 1982 in Bandung
and grew up in Purwakarta, the district adjacent to Karawang. Twenty days after her birth, she was adopted by a family who desperately wanted a daughter. Her unmarried biological parents were in junior high school when her mother became pregnant. Both families agreed that the mother and father should get married until the delivery, at which point the baby could be given away. After she was born, her parents divorced and a neighbor helped her parents to look for a family who wanted a child. Tika was adopted by a middle class family. She recounted her childhood:

Since I was little till primary school, I was rarely taken care of by my mom. She was a career woman, always working. My father too. So I was tended to by a neighbor next door. Every morning before they left for work, I was entrusted to my neighbor…. When my mom returned from work, she took me. The next day it was like that again until I entered primary school.

She never had contact with her biological parents, except once, when she was 22 years old. Tika met her true mother with feelings of anger and hatred. ‘It’s like I met a stranger… I don’t care anymore, she is nothing!’ she recounted.

Her step-parents worked in the same company but in different positions. Her mother was a secretary, her father a janitor. When they met, both were already married and each had a child. Tika thus has a step-brother from her mother and a step-sister from her father. In the family, she felt that only her mother really loved her. Her father and brother were always unpleasant towards her. Since kindergarten, her father often beat her. Tika vividly remembered the first time her father beat her.

There was no toilet in the kindergarten so I asked my maid to go home… I had stomach ache. Just arrived at home, my father was absent from work. He thought I did not go to school, then he beat me with a wooden stick that made [me] swollen in my legs and I couldn’t walk…. The reason my father beat me [was] because I’m naughty….

As she grew up, Tika realized that her father was not a good household head. Almost all household needs were fulfilled by her

---

51 I would like to thank Enrico for doing this interview.
mother, who had a good position, unlike her father who was then working as a security guard in another company. She was a spoiled child as her mother could afford to buy a house, a car, and a motorbike, and to employ a housemaid. Her disappointment towards her father grew as she learnt that he was a womanizer. Later, she learnt from her brother that her father frequented brothels.

Tika had no respect for her father and was traumatized by his misdemeanors towards her and her mother. She felt stressed at home. The family atmosphere affected her character; she became rude, and a tomboy. In junior high school she had more male than female friends. Yet, she was interested in and admired a girl in her class. Tika was still hanging out mostly with male friends in senior high school when she started to use drugs. Many of her male friends were IDUs. At first, she used pills like nipam\textsuperscript{52} and ecstasy, then marijuana and shabu-shabu (methamphetamine). One day, two friends persuaded her to inject putauw (heroin), saying it would give her self-confidence and peace. Thinking of the tension whenever she saw her father, Tika decided to try it. She started by using it once a week, which slowly became three times a day. At that time, money was no problem as she could spend one million rupiah (US$ 110) per week to buy putauw. ‘Since I used it, if [I] met [my] father [I] felt relaxed. If I didn’t use it, I was stressed as usual. I felt self-confidence’.

Her drug use had an effect on her sexual desire. Tika shared her experience:

I felt so horny every time I used [putauw]. When I had no boyfriend, I masturbated. In the second grade, I had a boyfriend. He was handsome and a user too.... With him, I began ML [making love]. My first ML was with him. I felt good. Every time we met, I could ML three or four times. The most pleasure [was] after [we] used [putauw], because I [was] so horny!

Approaching her final exam in the third grade, Tika became pregnant. She was depressed, confused, and frantic. Her parents were shocked and upset when she told them. As usual, her father beat her back so hard that it made a permanent scar. They suggested she have an abortion, which she initially refused. Her father promised to finance her college education if she aborted the

\textsuperscript{52} Nipam or Nitrazepam belongs to the group of drugs known as benzodiazepines.
fetus. After learning that her boyfriend did not want to be responsible, she finally agreed to the abortion on 3 April 1999.

She graduated from high school when her mother stopped working, which reduced her family’s income. One day her mother caught Tika using drugs in her room. Her mother’s first reaction was to cry. Tika felt sinful and regretful as she apologized to her mother. Although her mother became uncaring towards her, she still encouraged her to continue her studies in college. The first semester went smoothly until she used her tuition fees to buy putauw again. Tika was expelled. She felt extremely guilty about disappointing her mother again, who was often sick.

After dropping out of college, she seldom stayed at home and spent time with her peers in a hangout. There Tika met Dadang and they became sweethearts. When they agreed to get married, Dadang’s mother opposed it. But Tika and Dadang insisted on tying the knot.

His name is Dadang. We often chat and I like him because he is handsome and he doesn't use drugs like me. He only gets drunk. He is a Muslim but his family is Christian…. But his parents [are] divorced. One day he ‘shoots’ me and we become lovers. After a while, he asks me to get married. I agree because of love. I tell this to my parents, they agree too, especially my father. I know he agrees only to let me go. But Dadang’s mother disagrees because he is unemployed and has only graduated from high school. If we are married, how can he feed me, that's her thought. Finally she gives up. We got married on 9 November 2000. His elder sister doesn’t like me, so I decided to stay in my house.

Her new life after marriage was disappointing. Dadang had no intention to look for a job and often got drunk with his friends. Tika started to doubt his seriousness about having a family. Her pregnancy and delivery passed without attention from Dadang. After both her baby and her mother died, she got a job, but this only lasted for four months because she unexpectedly became pregnant again. Dadang, who was then working as a driver, gave her Rp. 15,000 a day for her daily needs. During this second pregnancy, she only once went to the doctor because Dadang had no money. She delivered with a private midwife nearby the house. Underneath her happiness about having the baby, she worried if something would
happen, like with her first child. But actually she was the one who fell sick:

After delivery, suddenly I started to get sick. From hot, continuous fever, hemorrhage, and other things. Those made me drop [feeling weak] and stressed. I had difficulty looking after my child. Luckily, my mother-in-law helped me. My illness was better when my child was three months. When I felt better, my mother-in-law took me traveling to Puncak…

After four months, her baby girl, Asih, fell sick with symptoms similar to her first child. The baby was confined for a week in a private hospital due to acute pneumonia. At the same time, Tika’s condition declined. This raised suspicions in her father, who began looking for information. He then suggested that Tika should go to a hospital in north Jakarta. In the hospital, the doctor asked whether she had ever used drugs, and he suggested a blood test. The doctor assumed she was HIV-positive:

Three days later I went back to the hospital to pick up the result. First, I was counseled. Then, [they] informed me that I was HIV-positive. I was notified this HIV had led to AIDS. I had to take medicine everyday. My God, I just cried at that time.

Gravely worried about whether Asih was infected, Tika could not bear to get her tested. When Dadang and his family learnt of her seropositive status, they treated her like an orang haram (orang means people, haram means something forbidden). She was isolated, which forced her to move back to her father.

At first Tika did not disclose her status to her father. She was afraid of his reaction. But after a while she decided to inform him. She was surprised with his reaction: ‘There was medicine for HIV, right? I knew you got it (HIV)…’ He continued, ‘Go to hospital again. Ask about the medicine, how much. If affordable, just buy it…’ Her father was supportive and told her not to worry about her daily needs. When she decided to test Asih, her husband also took the test. Asih was positive and Dadang was negative. Later, Dadang proposed a divorce and she agreed. Tika felt relief after the divorce and her condition improved somewhat. She also started ARV treatment, though it was quite expensive, about Rp. 380,000 per
month (US$ 44). Asih’s condition, however, deteriorated and she died in November 2003.

I was so sad. I felt deep loss. I just kept crying…. My father too, it was the first time I saw him cry. He loved Asih very much. He often cuddled her…. At that time I felt guilty to my child. Because I used drugs, she became [a] victim.

The deep sorrow that engulfed Tika made her stay at home. Her neighbors knew her seropositive status and that her daughter had died of AIDS. Tika felt their disgust. She understood that most people did not know much about HIV. When her father could no longer afford it, she stopped taking ARVs. In a month, her health declined. Her father called a doctor to the house but the doctor could do nothing. Her illness was too acute: hair loss, hemorrhoids, white patches, and wasting made Tika barely able to speak. Her neighbors said that she looked like an insane person. She just nodded or shook her head when talking to someone.

In her dying state, two people – Johan and Hari – from a hospital support group visited her. They encouraged her to fight the illness, maintain her spirit, and avoid becoming desperate. Three times a week they visited her, nourished her, and told her about the support group for Odha. Tika was relieved to know that she was not alone and began attending the support group meetings at the hospital. She learned a lot about HIV/AIDS and received free ARVs that helped her condition. Sharing her experiences in the group made her feel comfortable and relieved. She decided to join as a volunteer.

My experience as [a] motivator makes me understand the meaning of life. Before we die, we don’t stop trying. Odha really need support because it has [a] deep effect that makes us [want to] stay alive. I received Rp. 350,000 per month, plus meal and transport costs to do home visits…

Her relationship with Johan grew closer until one day she learnt that he was still using drugs. It was a secret since in the support group nobody was allowed to use drugs. One day over lunch she told Johan that she liked him. Johan was rather startled for he was a

53 The free ARV treatment program began in January 2004.
passive and shy man. Their intimate relationship resulted in pregnancy. Tika panicked and thought about abortion, but Johan disagreed. They talked to their parents and eventually both agreed to marry. Due to religious differences, they did *kawin sirri*.

Tika’s story reveals that coming from a middle class family and having a relatively good education does not protect one from HIV. As a drug user, Tika never knew about the risks of her behavior until she and her baby suffered recurrent illness caused by AIDS. Stigma and discrimination from her husband and his family created an even heavier burden. Fortunately, in the critical stage, members of a support group were able to wean her from desperation.

**Firman’s story**

Firman’s story is that of a male injecting drug user struggling against his addiction and trying to cope with his seropositive status. I first met him as a new outreach worker for a harm reduction program at Pantura Plus. We were introduced by Amang, the manager, on my second visit to the Pantura Plus office. Firman, 26 years old at the time and the eldest of two siblings, was quiet and soft-spoken.

I started use [injecting] drugs in high school, second grade. That was in 1997. At that time I went to a friend’s birthday party. It was getting late at night when I wanted to go home. But my friend whose birthday [it was] and two other friends insisted that I stay. Then we entered his bedroom. There I saw them injecting themselves. First, I was a bit scared looking at [the] needle. I remembered in the past [I] had been afraid of injection for smallpox. Let alone seeing blood that shook [in the syringe]...

He stayed at his friend’s house for five days and eventually tried *putauw*. His parents were angry when he returned home, pale and disheveled. He said it was only lack of sleep.

Firman’s father is a Sundanese, his mother a Javanese. From the age of two he lived with his maternal uncle in Madiun, East

---

*Kawin sirri* literally means ‘secret marriage’. It is a legal marriage according to Islamic law, but is not registered in civil law.
Java, until he finished the first grade of junior high school when he was 13 years old. His uncle was married for several years but had no children. There is a belief among Javanese that a couple who has no child after several years of marriage must raise a relative’s child in order ‘to hook’ their own. Firman felt that his uncle and aunt loved him as their own. He vividly remembered the good days of his childhood in Madiun. Although he spoke Sundanese in Karawang, he did not forget the Javanese that he had learnt in primary school.

When he returned to Karawang and entered public school, Firman was shocked by the atmosphere. His new friends were straight to the point when talking to each other. For Firman, who had internalized Javanese norms, Karawang people often seemed ‘rude’. His friends called him ‘Jawa’ because of his ‘Javaness’.

Firman became addicted to putauw and it deeply affected his life. He began using drugs (marijuana, pills) and drinking liquor in junior high school. In the second grade of high school he started using putauw, but not through injection. Between 1998 and 2000 he was heavily addicted, injecting putauw three to four times a day. He said that he was only thinking about himself and did not care what his parents told him. His younger brother, Endang, was addicted too. The only thing on his mind was how to get money to buy putauw since he was only a high school student.

[The] daily stipend from my parents was not enough. So I started [to] take things from my house. First, from my own room, then other rooms... whatever I could sell. But I never took from other houses. Sometimes I asked for money from friends or somebody I knew.

Firman bought putauw either in Karawang or Jakarta. One day, in September 2000, police arrested him while buying putauw in Jakarta and locked him up for three months. At that time, drug raids were not as frequent as they are now. Later on, his brother was also arrested during a drugs transaction. His time in jail led Firman to think about his life. After getting out of jail, he kept asking himself whether he would be like this forever. He did not know why, but getting putauw became difficult in 2001. It was expensive; he had to share it with friends. He decided to ‘pasang badan’ (tame the body) and go clean.
Firman stayed at home for more than a month, avoiding his friends. It was painful, particularly when he was sakaw\(^{55}\) (suffering from withdrawal symptoms). He even fell sick with diarrhea. In 2002 he was ‘clean’ and stayed with his uncle in Madiun. When he returned to Karawang, he got a job at an optical shop for a year until he was fired when his employer caught him using drugs. He relapsed and became unemployed. Firman admitted that it was hard to stay away from putauw when it was right there in front of him. His neighborhood was not a good environment since many unemployed young people were using drugs. Nevertheless, his addiction was not as intense as before.

Being unemployed did not deter Firman from having a girlfriend. She worked in a company and lived in a boarding room. He often stayed overnight at her place. She knew that he was an IDU. He remembered his sexual relationship with her to be wonderful, full of passion and love. Yet, their relationship ended after a year when she decided to return to her hometown in Bandung. Sometime in 2005, Firman was introduced to Tanti by a friend. She worked in the optical shop where he used to work. Tanti, 20 years old, was cheerful, witty, and easy-going. Firman liked her very much; in a few months, they were lovers. He considered the relationship serious and thought of marrying her someday.

One day, Firman’s friend Santosa asked him to visit YPI. Santosa had not said anything about HIV. At YPI, Firman was confronted by posters and brochures on HIV and drugs. After this first visit, he came to YPI several times with Santosa. He began asking a counselor questions and was offered an HIV test. Not feeling ready for it, he declined. But Santosa continued to inform him about HIV/AIDS and persuaded him to get tested. Some of Firman’s friends had already done so. In January 2006, he agreed. He told his parents that he may have contracted hepatitis and wanted a lab test. After a week, during post-test counseling, Firman was informed that he was HIV-positive.

When I found out, I was shocked and didn’t believe it. For about a month I contemplated. Why I got it... slowly I tried to accept it. I often shared with friends, for example with Leo who had already disclosed to his parent. How he did it,

\(^{55}\) Sakaw is derived from ‘sakit’ which means ‘sick’.
what he felt, etc…. Because I had friends with the same fate, I felt calmer.

His brother was infected too, but neither told their parents. In mid-2006 Firman joined the Pantura Plus harm reduction program as an outreach worker. He brought home brochures and leaflets about HIV/AIDS and deliberately put them in places where his parents would see them. He used similar tactics with Tanti. Tanti knew that he worked at an HIV/AIDS organization. Firman expected her to understand that as a drug addict, he was at risk. But she did not respond as he expected.

I'm confused. Her parents are pushing me to marry her. Yeah, they consider me as their own child. But I'm not ready. I am still hesitating whether to tell her [about my HIV status] or not. [I am] afraid of her response. I often talk to friends or the counselor, but I don’t know... I’m confused.

Firman further stated that if he married Tanti without disclosing his seropositive status, he would use condoms. But he would find it hard if Tanti asked him why he always used them. Perhaps he would tell her he wanted to delay having children until their finances were in better shape. In the midst of his confusion, Firman decided to disclose to his girlfriend and ask her to do an HIV test. He would re-test too. If they married he would also do a CD4 test to reduce the risk of transmission to his wife, and use condoms. He also said he would understand if Tanti decided to end their relationship.

Firman finally married Tanti in late December 2006 without disclosing his seropositive status. He said he had to avoid hurting Tanti’s feelings.

At that time I didn’t think about my status. I felt glad, so happy. Friends gave me advice [to disclose]… but the time was not right. Invitations had already been sent… you can’t do that when everybody is happy.

Firman was happy when his wife immediately became pregnant. But Tanti grew suspicious and asked him whether he had tested for HIV or not. She had seen some of his junkie friends pass away, although she did not know that their deaths were caused by AIDS. Firman remained indecisive about disclosing to her.
When Tanti’s pregnancy reached its seventh month, the police apprehended Firman while he was hanging out with two friends. One of them had putauw in his pocket and they were all locked up. He looked gloomy when I interviewed him in prison in early December 2007. He had already been sentenced: one year and six months. Firman told me that Tanti had taken an HIV test at Pantura Plus before she delivered. He was very relieved to learn that the result was negative. His younger brother, however, died when he was in prison. His wife and baby stayed with his parents.

Despite being able to think positively about his seropositive status, certain symptoms caused him to worry. When he experienced throat pain or skin rashes, he would wonder whether these were the initial symptoms of AIDS. Firman had seen some of his IDU friends die from overdose and severe illness. Although it was not certain whether they had died of AIDS, he assumed this was the case; their symptoms had included swollen lymph nodes and wasting. Firman felt lucky he had never suffered serious illness. After he tested positive, he tried to change his bad habits, such as begadang (staying awake at night) and drinking. He forced himself to go to sleep early, took walks in the morning, and began eating a healthy diet. But one thing that he could not completely stop was using drugs.

Firman’s story describes a typical male IDU introduced to drug use through peer pressure. His story reveals the dynamics of stigma and silence that appear so often in the stories of Odha, particularly concerning their relationships and reproductive desires.

**Conclusion**

Dina, Nani, Tika, and Firman are ordinary people who were unaware of the risks of HIV infection. Their stories show that young people in Indonesia are not receiving adequate information about HIV/AIDS, and that the lack of prevention initiatives among the general population makes family members of high risk individuals more vulnerable. Many of the women in this study found out their seropositive status only when they or their husbands and children became severely ill. Indonesian society is thus witnessing a silent
epidemic. Stigma and shame surrounding being an Odha are salient in these stories, forcing Odha to adopt tactics to avoid disclosure in their social relations.