Life and death with HIV/AIDS: life stories from Karawang, West Java
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Chapter 5

Confronting Ill-Health and Stigma

This chapter presents the illness narratives of several Odha. It identifies how they cope with HIV/AIDS in the context of their families, their peers, and the community at large. How does HIV/AIDS affect their daily lives? How do Odha living on the margins of society respond to the challenges of making a living? In this chapter, I argue that the intersection of ‘deep illness’, fear of stigma, the vagaries of family support, economic hardship, and fragmented healthcare leads to Odha leading precarious lives, which can result in death. These intertwining concerns will be revealed through the illness narratives of four Odha whom I followed during fieldwork.

I first present the illness narratives of several Odha and analyze them using Arthur Frank’s framework of deep illness (1998). Fear of stigma and disclosure are dominant themes in the narratives, along with fear of sickness, which is always linked to economic hardship. I therefore discuss the tactics (de Certeau 1984) developed by Odha to cope with economic hardship in their daily lives. I also discuss how stigma and disclosure intertwine with social support from the family, and how economic hardship hinders access to healthcare.

Narratives of illness

Illness is the subjective experience of physical or mental states, whether or not they are based on underlying disease pathology. The experience of illness is not limited to the symptoms but includes reactions from one’s social environment, such as stigma, discrimination, and exclusion. Perceptions, feelings, and responses to sickness are discussed as the meaning response, ‘the psychological and physiological effects of meaning in the treatment of illness’ (Moerman 2002:14, original emphasis). Kleinman states that illness is polysemic or multivocal – it carries more than one
meaning (1988:8). ‘Emphatic witnessing... of the patient’s and family’s stories of the illness’ (1988:10) should therefore be central to clinical work.

Frank (1998:197) defines deep illness to be:

...perceived as lasting, as affecting virtually all life choices and decisions, and as altering identity. The essence of deep illness is to be always there for the ill person, and the ill person believes it always will be there.

Frank suggests that there are three dominant stories told by people who suffer ‘deep illnesses’. The first is the popular restitution narrative, whereby an individual becomes ill and, through the efficacy of medical intervention, regains health. The second, the chaos narrative, is filled with uncertainty and confusion as the ill person is unable to portray his/her life as a story with any narrative ordering of beginning, middle, and end (1998:202). It reveals a series of negative life events that contribute to the experience of illness or are exacerbated by its presence. Third, the quest story implies transformation through illness. Illness here is lived as ‘a condition from which something can be learned, and this learning can be passed on to others’ (1998:203). For instance, many people who have suffered cancer are not happy that they had it, but are grateful that it changed their lives (Frank 1998:203). In the quest story, it is not always necessary to regain health, as it is in the restitution narrative. These three kinds of stories are not clear cut; in most illness narratives they intertwine.

We begin with Nani’s case (see Chapter 4 for her life story) as an example of a quest narrative. ARV treatment was obviously effective for her: it helped her stay healthy. Her CD4 count was 75 after recovering from severe opportunistic infections at the end of 2003. In February 2004, she took another test when she attended the Fourth Odha National Meeting in Surabaya; the result then was 275. Nani was constantly concerned about her CD4 count, though she could not afford to have it checked regularly. Like most Odha in Karawang, she waited for free CD4 testing, either from an NGO or a government program. After almost two years, she did another test and the result was 276. ARV adherence was crucial for Nani, and influenced her perception of health. One day in September 2006, I met her in Klinik Kita. We sat on a sofa in the middle room and she
told me about the chest pain and wheezing she had experienced that morning.

Yesterday afternoon I forgot to take [my] ARVs. [I] just remembered this morning when I took them. I'm afraid that the pain [is] because I was late to take the medicines. I think [that is] why my body is...

I asked Nani what she felt besides chest pain. She said she also experienced cold sweats, pain in her bones, and difficulties sleeping. She had already talked to Idham, a counselor at Pantura Plus, and he had said that she probably needed to replace her ARV combination – Duviral and Neviral – with another one. The way she told me about her illness and her facial expressions revealed that she was quite worried. Later, Idham came to the clinic and Nani asked him to do acupressure to ease her pain.

A few days later I asked about her illness via text message. She replied, 'It’s worse. My chest is so painful'. When I visited her rented room in Cikampek – about one hour from Karawang town – she was sitting on the mattress on the floor, pale and a bit thinner. She was coughing and wheezing; sometimes her breath sounded heavy. Several times she spat into a small bowl which she kept under a wooden box next to the mattress. She said she had no appetite. The previous Friday, Nani had met a doctor in puskesmas Karawang who prescribed some medicines and a lab test. The result showed her hemoglobin and leukocyte levels to be below normal, and she interpreted this to mean that her CD4 count was going down. She only bought one prescribed medicine – though the doctor had prescribed two – because she had no money. She would receive her transportation fee the following week and would buy the other medicine then. Her friend, Gumilar, bought her Sangobion pills for increasing hemoglobin.

I never felt drop (fragile) like this time. Is it because of low CD4? I want to see Dr. Samsu…. When [I] wake up I feel dizzy. Always sweating, like when I started to take ARVs. Sometimes [I] throw up after eating or in the morning. [My] hair starts to fall [out]. No appetite, my mouth feels bitter.
Three days later, I called her and she sounded happier. She said she felt better, and was even ready to do outreach work. I asked whether she had finished her medicines. She replied, ‘I didn’t finish them. The smell is bad. [They] make me nauseous’.

During my research, I only once saw Nani fall sick for more than a week. Sometimes she got a mild cold or headache, which she treated with popular medicines such as Panadol or Poldamic (analgesics). Besides ARVs, she consumed vitamins – Stimuno (immune booster) and Curcuma (turmeric) – to maintain her stamina as she was often doing outreach until late in the evening. Curcuma is also good for maintaining appetite. One morning in October 2006, we talked in her room and she recounted a recent experience.

I experienced stigma at puskesmas Karawang. A few days ago I was drop [fragile], sick, because of it [the stigma]. Initially only Dr. Ana knew [her status]. While the nurses, like Ibu Yani, didn’t know. When they found out who I am, their attitude changed... I can’t accept it. Suddenly I dropped. Gumilar said, ‘Don’t worry about it’... I even told Dr. Andi when I met him...

(Me: What was their attitude?)

Usually we chat, now they keep distance. We [used to] wear mukenah\(^{56}\) together, now they use other mukenah. It means [they] don’t accept [me]. So I feel like how can.... They don’t know who I am. They only know about Atma [another Odha].

Though she tried to ignore it, she had to meet the people whom she felt were stigmatizing her almost every day in her outreach work.

Nani’s story is a quest narrative: she had regained her health through medical treatment and this had transformed her life into one focused on HIV activism. She tried to lead a ‘positive life’, an idiom always echoed to Odha by NGOs. Yet, Nani’s narrative also reveals the workings of social stigma surrounding HIV/AIDS. The change in attitude of some nurses affected her psychological and physiological state. She only disclosed her seropositive status to a limited circle – her family, her husband, some friends and colleagues – but kept silent to others for fear of stigma. Silence is also a form of narrative which, using Drakos’ term (2008), can be seen as a ‘broken

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\(^{56}\) Mukenah is a white head-to-toe cloak worn by female Muslims when praying.
narrative’, revealing the tension between the demand for silence and the desire to talk. In this context, perceived stigma\textsuperscript{57} is embodied in silence, an expression of how people in certain situations feel prevented from speaking openly about their experiences of illness (Drakos 2008:101).

Nani believed that ARVs were effective, helping her lead a positive life. Her desire to get married and have children was encouraged by the efficacy of ARV therapy and the other benefits derived from NGOs such as YPI, Pantura Plus, and Klinik Kita.

Rudi, an ex-junkie, found out that he was HIV-positive in March 2005 when he fell sick for about two months. He initially thought that his illness was caused by sudden withdrawal from drugs. Before testing for HIV, he saw a doctor in a private hospital and was diagnosed as having typhoid and pneumonia. But though he took all the prescribed medicines, he did not recover. A YPI outreach worker for IDUs then suggested that he get tested for HIV. Following post-test counseling, a doctor immediately prescribed ARVs – a combination of Duviral and Neviral – simply based on his symptoms. In December 2005 he took his first, free CD4 test. The result was 92. What did he feel about the ARVs?

When I found out the result, I only thought one [thing], medicine... how to get healthy. [I] can [keep] working, thinking, planning... that’s all. If there is medicine [to be] healthy, it means you can think, play...

The effect [of ARVs] is good. I [am] seldom sick now. Its side-effect is [to be a] little itchy... I feel itchy though I can hold [myself] not to scratch... then nausea. Sometimes I get headaches when I feel tired...

For the itchiness, Rudi used hand and body lotion. One day he consulted the doctor from Family Health International and asked why he still experienced nausea after almost a year of taking ARVs. The doctor advised him to take the ARVs about half an hour after eating (in the morning and evening). He followed this advice and the

\textsuperscript{57} Thomas (2006) suggests three kinds of HIV/AIDS-related stigma. The first is \textit{self-stigma}, which occurs through the self-blame and self-deprecation of those living with HIV/AIDS. \textit{Perceived stigma} refers to the stigma individuals think they will experience if they disclose. \textit{Enacted stigma} refers to the active discrimination individuals face due to their HIV status.
itchiness subsided; the nausea persisted. To maintain his health, Rudi also took multi-vitamins like Fatigon, Redoxon, and Neurobion.

Rudi perceived HIV to be like any other disease; the main difference was that it was a lifelong condition. ‘I just get along with it. I don’t think about HIV’, he said. He did not automatically associate coughing, flu, fever, or other illnesses to HIV weakening his immunity. Rudi had disclosed his seropositive status to all members of his nuclear family. He argued that PLWHA must not keep their status secret; this only keeps lay people misinformed about HIV and AIDS. If people learn enough about HIV, it will reduce the stigmatization of Odha. Despite this, Rudi remained ambiguous about disclosure. I asked him, ‘If you fall sick and need to go to the hospital, would you disclose your status to the health provider?’ He replied:

I don’t think so… I don’t think so.

(Me: Why?)

…let them serve us like any other patient without… without reluctance… rather than constraining the service.

His answer reveals his doubts about healthcare providers, who often discriminate against Odha.

In his first year of ARV therapy, Rudi maintained relatively good adherence, though sometimes he was late or forgot to take the medicines. He felt in good health and was active as an outreach worker for IDUs at Pantura Plus. Later he became the case manager. Once a month he went to Dharmais hospital in Jakarta to pick up ARV medicines for Odha in Karawang. He was also in charge of referring Pantura Plus clients to the puskesmas or hospital when necessary. In the meetings between Pantura Plus, other NGOs, and local government officials, he often expressed his opinion on HIV prevention matters. I once asked him whether he worried about his current life. He replied:

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58 Fatigon is a food supplement to maintain one’s stamina and health.
59 Redoxon is a combination of vitamin C and zinc to maintain a healthy immune system.
60 Neurobion is a multi-vitamin to maintain the nervous system.
What I’m worried about… mmm… now I feel [my body is] good but [it] is not impossible that someday [I] will fall sick. My hope is there are other ways to get more income. That’s all to prepare… Euis [his wife] is afraid of [getting] sick, I’m afraid of [getting] sick, and Wawan [his son] has not tested yet…. That’s all my hope.

Now medicines are no problem, but if there is [a] change of government, change of people, I’m afraid the medicines will not be free anymore…

His answer reflected his uncertainty about his economic status, his health, and the quality of HIV/AIDS treatment in the future.

In his second year of treatment, Rudi still experienced side-effects and began missing his ARV doses. In addition, he occasionally relapsed and injected drugs. He did not tell his wife Euis about this. When I met him in December 2007, Rudi looked thin and pale. He had done a CD4 test a few weeks before, and the result was 10. I was unable to question him further since he was in a hurry to take someone to the hospital. The cause of the declining CD4 count, as Euis told me later, was Rudi stopping ARV therapy.

He isn’t frank with me. He used to be disciplined [in taking ARVs]. Then he stopped… I don’t know for how long. I often ask, ‘Have you taken [your] ARVs?’ He says yes… but he often lies. I [was] shocked when [I] heard his CD4 [was] only 10. From 38 to 10. I couldn’t sleep all night thinking about him…

(Me: Why did he stop?)

Well, he said nausea, itchiness… its side-effects…. He has thrush too. So I told him, get the therapy now… and keep your health.

Adherence to ARV therapy is difficult for many Odha who are still injecting drugs. They are often preoccupied by their addiction or are struggling to stop.

At the onset of ARV therapy, Rudi’s narrative reflected his optimism for the future: he disclosed to his family, felt in good health, and was active in HIV prevention work. In Frank’s terms, Rudi’s story was a quest narrative. But his story gradually shifted to one of uncertainty: of concerns about future income, fear of sickness, and
the availability of medicines. This change must be understood in relation to the context of unemployment and the sustainability of the HIV/AIDS program in Karawang. Rudi was aware that international funding agencies were the main supporters of HIV/AIDS prevention programs in Indonesia. According to the Country Report on the Follow Up to the Declaration of Commitment on HIV/AIDS (UNGASS) 2008-2009, 39% of expenditures were borne by the domestic/public sector and 61% by international sources (National AIDS Commission Republic of Indonesia 2009). Rudi’s concerns over income were inseparable from his worries about falling ill. Accessing health services requires money; 53% of health financing in Indonesia in 2008 came from private sources, of which 67% was out-of-pocket payment (WHO 2009). A recent study in Yogyakarta and Jakarta found that Odha spent, on average, respectively 68% and 96% of their monthly health expenditure on HIV-related care – a heavy burden for many ARV patients (Riyarto et al. 2010).

The supply of ARV medicines fell behind several times in 2007 and 2008. Rudi revealed that in November and December 2007, the stock of ARV medicines at Pantura Plus was only enough to last one week; this meant that Odha on ARV therapy had to come to Pantura Plus every week, not every month as usual. But in some places delays were worse. An Odha from Jember town, East Java, complained via AIDS-INA, the Indonesian AIDS mailing list, that his therapy was interrupted for two weeks because ARV medicines were out of stock in the local hospital. In April 2008, Budi, already under ARV therapy for four years, calmly told me that he had not received his medicines for a week. If universal access to treatment is to be attained, the government will need to address problems in the supply chain for ARVs.

Taufik’s story showcases another kind of narrative. A high school graduate, unemployed, and an active IDU, I met him for the first time when he joined Pantura Plus’ harm reduction program in October 2006. He was assigned as an outreach worker for inmates in Karawang district prison, a place he knew well. In 2000, the police

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61 AIDS-INA is the most popular mailing list for HIV and AIDS issues in Indonesia. Its website is www.aids-ina.org.
62 President Bambang Susilo Yudhoyono admitted in April 2010 that three Millennium Development Goals would be difficult to attain by 2015: improving maternal health; combating HIV/AIDS, malaria, and other diseases; and ensuring environmental sustainability.
had arrested him for carrying 10 mg of *putauw* (heroin); the court sentenced him to a year in prison. The time in jail did not curb his drug use. In 2003 his parents sent him to a *pesantren* (Islamic boarding school) for rehabilitation. This did not work either; he escaped after a week. One day he met Rudi, who introduced him to YPI and provided him with information on HIV and AIDS. Taufik was tested for HIV at Pantura Plus in April 2005. The result was positive. ‘What did you feel at that time?’ I asked him.

Normal. This is real, not [a] dream… inside myself [I] said, what you face is real life, you have to move on…. You don’t give up…. Don’t give up because HIV-positive [people] are not sick people…. Do something while my body still has immunity.

I just accept it. No regrets or else. [I] share [my status] with friends too. I have enough information to disseminate to other people. Don’t spread the virus to other people…

Being HIV-positive did not stop Taufik’s drug addiction, though he began using drugs less frequently. He told me that he had yet to fall sick. Nevertheless, he felt fragile when he saw his friends die of illness or overdose.

It’s in (my) mind…. if I’m dying like the other boys. Thin body. [I am] afraid that my parents can’t afford the cost of [me falling] sick. If you have money it’s no problem.

Taufik generally had a positive attitude. In interviews, he emphasized the importance of disclosure to raise awareness. A year after testing he disclosed to his immediate family members, who were already well informed about HIV/AIDS. Nor did he hesitate to disclose his status to the IDUs in the outreach program. Nevertheless, I recall a time in November 2006, in the midst of an HIV/AIDS workshop in the penitentiary, when Taufik sat down next to me. He was nervous; he had been asked to give a *testimoni* (testimony) as an *Odha* to the penitentiary’s officers. This was his first *testimoni* to an audience outside Pantura Plus. When he came forward to do the *testimoni*, Taufik’s voice was soft; he was stammering. But his conviction that sharing correct information about HIV/AIDS would reduce stigma and discrimination spurred him on to relate his life story.
His CD4 count was 156 when he took the test in January 2007. He started ARV therapy a month later.

After [the] CD4 test, I was persuaded by Amin [a counselor] to take ARVs. I observed my friends. I assumed that if you take ARVs when you’re sick, the side effects appear. But if you take them when you’re in good health, there are no side effects. So I decided to take them….

I took Duveral Neviral for three months. The first two months I observed [adhered]. The last one month was not regular….

(Me: Why did you stop?)

Well, perhaps influenced by [the] question, what is the efficacy of ARVs? What are ARVs for? What is attacked by ARVs? What’s treated? I started to not believe [in] ARVs, so [I] just stopped. I’m okay till now, thank God…

Since he was still injecting drugs, Taufik started subutex (buprenorphine) substitution therapy, delivered by a private physician. This reduced his weight from 65 to 59 kilos. When he was taking ARVs, he had enjoyed a good appetite and gained weight.

More recently, Taufik had entered into a relationship with a girl from his neighborhood. She knew he was a junkie, and as they became more intimate, he disclosed his seropositive status to her. Her positive reaction was unexpected; Taufik had thought she would break off the relationship.

In the beginning, Taufik’s narrative was similar to Rudi’s: both approached their illness with a positive attitude. Taufik’s involvement in the harm reduction program allowed him to care for others. But his illness changed his behavior only slightly: he began using sterilized needles, but continued with his late nights of drinking and drugs. Taufik’s testimonies are central to his narrative, illuminating the dynamics between stigma and disclosure. During my fieldwork, I met only one other individual who had given testimony to audiences outside Odha support groups. Very few Odha – even those active in HIV/AIDS prevention work – risk disclosing their status to the broader public, especially in their communities. Taufik’s nerves before giving testimony were probably triggered by the fear that penitentiary officers who knew him as an outreach worker would now know he had HIV, for which he could be stigmatized.
Although he accepted his fate as an *Odha* and cared for others through the harm reduction program, Taufik did not seem to care for himself. By stopping ARV therapy, he revealed uncertainty about his future, though he surely knew that ARVs worked well for other people. Like Nani and Rudi, economic concerns and fear of illness came together in Taufik’s narrative; he was well aware that his parents could not afford expensive treatments. There is an expression in Indonesia, *sadikin*, which is short for *sakit sedikit jadi miskin*; it literally means ‘you have sickness, you become poor’. Taufik and Rudi witnessed Atma, a fellow *Odha*, die of AIDS at home because he had no money to access the health service. When the poor fall sick, they have no access to care.

Atma, a 25 year old ex-junkie with a wife and two children, had been an outreach worker in *lokalisasi SR* (the brothel in Karawang). An injecting drug user between 1998 and 2003, he relapsed in June 2004 when he was working as a waiter in a bar, using ecstasy and *shabu-shabu* (methamphetamine). After he quit the bar job in August 2005, his friend introduced him to YPI. In October 2005, he was tested for HIV and found to be positive. Atma fell sick in September 2007; the doctor diagnosed severe TB, a common disease among IDUs, the so-called double infection of TB-HIV. His friends in the support group took care of his *Gakin* (short for *Keluarga miskin* or ‘poor family’) card\(^63\) so he could be admitted to the district hospital. When he returned home, Atma was not fully recovered. He had no income for his daily needs and often asked Rudi and other friends for food. Though his condition was deteriorating, he could not afford hospitalization. Rudi said that the *Gakin* card could not be used for a second time for in-patient services. When he could only lie down in bed and it was difficult for him to eat, Euis made him jelly. In mid-November 2007, I received a text message from Bahrul: ‘Our friend Atma passed away this morning. May God bless him’. Afterwards, I learned that his wife and children were living with his parents.

Atma had kept silent to his family about his seropositive status, and had only told them he was suffering from TB. Some *Odha* told me that Atma was in denial about his seropositive status from the very beginning, which made him refuse medicines. His CD4

\(^{63}\)The *Gakin* card for poor families allows them to access all public health services from *puskesmas* to provincial/national hospitals for free.
count was 78 when he fell sick, the only test he took after he found out he was HIV-positive in 2005. Though the doctor advised him to begin ARV therapy and Rudi tried to persuade him numerous times, he always refused.

**Coping tactics in daily life**

Being *Odha* in West Java is a daily struggle for survival. As most *Odha* come from poor families, earning an income is essential to meet one’s basic needs. Without special skills, many are engaged in NGO activities as outreach workers. People living in environments that limit their choices still exercise agency; they develop what de Certeau terms tactics (de Certeau 1984; Scheper-Hughes 1993). As we will see below, these tactics allow turning the events of daily life into opportunities.

At 4:30 pm on a blistering afternoon in September 2006, outreach workers and staff at Klinik Kita were preparing to go home. Nani and Atma, both outreach workers, looked upset as their pay had been delayed. The financial officer had not returned to Klinik Kita after running errands outside the office. I saw Atma approach Gumilar and ask for Rp. 2,000 for the bus fare. Nani likewise didn’t have enough money to get home by bus. She asked Gumilar if she could have a ride, for he also stayed in Cikampek. Gumilar, however, was not going home right away. Nani then left Klinik Kita and told me that she would hitchhike in one of the company buses, whose drivers she knew. She had to manage her daily expenses with care; her salary barely met her monthly needs. Nani rented a room for US$ 13.50 per month and often sent money to her mother in Cianjur. Rusdi, her husband, also had a small income and had to support his first wife and son.

At Klinik Kita, I often saw Nani and her friends share food during lunch. When she had just received her salary, Nani would sometimes order a meal for herself; nevertheless, minimizing her expenditures on food and transportation was an ever-present concern. She and her friends usually ordered food from one of the eateries behind the clinic: a plate of rice with vegetable/chicken soup, or fried fish/chicken and a few slices of fried *tempe* (fermented soybean); a bowl of noodles with meatballs or egg; or a plate of...
gado-gado (mixed vegetables with peanut sauce) with rice or lontong (rice wrapped in banana leaves). A meal shared with Zaki, Atma, or Inung cost her about Rp 5,000 (US$ 0.60). Sometimes she jokingly asked the field coordinator or VCT counselor to treat her to lunch, which they sometimes did.

One day when I was visiting Klinik Kita, Nani asked me for a favor. Her mother was sick and needed money to see a doctor. She asked whether she could borrow Rp 500,000 (US$ 55), which she would repay in installments. That weekend she would go home to take care of her mother. As a friend, I lent her the money. Nani had no savings to cope with adverse circumstances.

Unemployed, Atma decided to volunteer at YPI and joined the Pantura Plus support group. When Klinik Kita began its HIV/AIDS intervention program for female sex workers in early June 2006, Atma was recruited. Like most Odha I knew in Karawang, Atma came from a poor family and never had a steady job. As a high school graduate with no special skills, getting a job was no easy task; his involvement with Klinik Kita allowed him to escape the immediate pressures of daily survival. He received about Rp. 1,000,000 (US$ 110) per month as an outreach worker, not really enough to meet his family needs. In February 2007, Atma decided to buy a motorbike, on installments of Rp. 459,000 (US$ 50) per month. This meant that almost half of his salary was used for the motorbike.

Due to his poor performance over the first year of the HIV/AIDS prevention program, Atma’s contract was terminated in May 2007. Disappointed and confused, Atma now had difficulties supporting his family; his motorbike installments were taken over by someone else. Though he received some money from Klinik Kita for two months to meet his family needs, in August 2007 he had to start asking his friends for help. Rudi, the case manager at Pantura Plus and a good friend of Atma, told me that he often came to his house to ask for rice, food, and money. One day, Rudi attended a harm reduction training in Bandung. Atma knew that Rudi would be reimbursed that day and waited for him at his house. Rudi understood Atma’s intention and gave him Rp. 50,000 (US$ 5.50). But Atma reacted angrily. He shouted, ‘What? It’s not enough for my family!’ and threw the money back. Rudi gave him another Rp. 50,000. Rudi could understand Atma’s frustrations over meeting his daily needs; his own condition was hardly any better. Rudi complained to me about how he often had to help other Odha meet
their basic needs. As an activist and case manager, HIV-positive junkies turned to Rudi for help. Euis, Rudi’s wife, told me that Atma was experiencing depression particularly because of his financial problems.

Budi’s story is one of survival. In 2004, he was fired as a security guard in an automobile company after a severe bout of HIV-related illness revealed his seropositive status. As an active IDU turned AIDS volunteer, his life was not easy. His income was inadequate to support his wife and son and to meet his drug habit. After he divorced Neneng and remarried with Leni – an HIV-positive woman from Jakarta – in March 2007, Budi rented a room in Cikampek, next to Nani’s room. A month later, he and Leni were sharing a 2.5 x 4 meter room with Inung, another outreach worker from Klinik Kita, to minimize expenses. In September 2007, as Leni’s pregnancy progressed, Budi decided to move to Karawang town for easier access to healthcare. They rented a 2 x 2.5 meter room for Rp. 125,000 (US$ 14) per month. Though he still worked at Klinik Kita as a case manager, he also looked for other sources of income. He often worked as an illegal roadside parking guard, not far from the Pantura Plus office. He could get between Rp. 10,000–20,000 for half a day, which was enough, according to his friends, to buy a small amount of putauw. Less than a month after Leni delivered a baby girl in December 2007, Leni’s mother took the baby to her home in Jakarta. Though free formula milk was available from YPI, Budi told me that he could not afford to feed the baby. He and Leni were fortunate that Leni’s mother was taking care of their baby girl.

In Indonesia, it is common for grandparents to be involved in the raising of grandchildren. The HIV/AIDS epidemic, however, has added another dimension to this custom. When parents fall severely ill or pass away, grandparents must take full responsibility for their grandchildren. Both Budi and Leni moved into Leni’s parents’ house in Jakarta when Budi could not find a regular job. Less than a year later, Leni prematurely delivered another baby girl. One month after the baby’s birth, I arrived at their house just when Budi was about to leave. Looking skinny and gloomy, he clutched a guitar in his right hand. Later, Leni told me that Budi did ngamen (singing in public places) to make a living. She seemed to be suffering from a respiratory infection, indicated by shortness of breath. Her newborn lay on a mattress on the living room floor, warmed by a light bulb. She and Budi slept in the living room as well.
In November 2006, I had a conversation with Rudi, Firman, and Arif – a VCT counselor – about the harm reduction program at Pantura Plus. After discussing its constraints in the field, Rudi and Firman changed the subject. They were worried about the Family Health International-funded program ending next month. Nani was likewise worried that the HIV prevention program for female sex workers, also funded by Family Health International, was scheduled to end in December 2006. Over lunch at a small eatery, Bahrul – another VCT counselor at Pantura Plus – shared his observations about the many Odha engaged in the HIV prevention program.

They easily feel insecure about their jobs, particularly when they hear that the program [is] almost finish[ed]. It turns them down, in spirit, in doing outreach…. [I] can understand because they don't have other resources. For some, no job means no money to buy (illegal) drugs…

Bahrul often had to listen to the complaints of Odha at Pantura Plus. As we saw in Chapter 3, many IDUs had begun their addictions at a young age. Most of them had only finished high school and had difficulties finding work in Karawang’s industrial zone. Migrants with better educations even took the blue collar jobs.

To make ends meet, Budi, Nani, and Atma shared living arrangements and food, turned to their social networks of relatives, peers, friends, and colleagues, and looked to the informal sector for cash earning opportunities. Not having enough resources to maintain their health and support their families often led to frustration and depression; daily survival remained in question even as their physical health improved. This economic hardship, intertwined with the fear of stigma, loss of family support, and fragmented healthcare, often results in Odha leading precarious lives.

Support from family

The dynamics of stigma and disclosure must be seen against the background of death from AIDS. Some Odha who disclosed their seropositive status to their families encountered no discrimination
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from other family members. Nani, Rudi, Dina, Budi, and Taufik were accepted by their families as *Odha*. Disclosure within families, however, has its boundaries; usually it is to the nuclear but not to the extended family. Emotional support from family members may enable *Odha* to live positively, particularly if they have acquired understanding about HIV and AIDS, as was the case with Nani, Dina, and Budi.

Chandra’s case illustrates how some families devote their resources to the care of AIDS patients. I met Chandra in one of the support group meetings in Pantura Plus in September 2006. He was 25 years old, a college student from a middle class family. He was good looking, tall, and slender. He had learnt his HIV status in July 2006 and joined Pantura Plus as a volunteer. He was easy going, often joking when I saw him among friends. Chandra never disclosed his HIV status to his family, though he felt close to his mother. In November 2007, he married Yuni, an administrative staff member at a private computer academy.

After more than a month of not seeing him, Rudi told me in late January 2007 that Chandra had fallen ill. A week earlier, Chandra had seen a doctor in a private hospital who advised him to go to Dharmais hospital. On a rainy day, Rudi and I visited him; his house was just 300 meters from the Pantura Plus office. His mother welcomed us and we followed her to the living room. Chandra was lying on a mattress in front of the TV. Next to him, his younger brother was watching a film. Chandra’s eyes were shut when Rudi called to him; his hand felt warm when I shook it. He closed his eyes again and covered himself with a blanket. Black blotches (probably a symptom of *Kaposi sarcoma*)\(^{64}\) were apparent on his face and arms. ‘His CD4 is 19’, Rudi said to me. His mother told us that Chandra was finding it difficult to eat and often vomited, so she had to blend fruits for him. ‘He doesn’t open [up] to me’, said his mother, despite her expressed readiness to accept whatever was wrong with him. The next day Rudi accompanied her as she took Chandra to Dharmais hospital in Jakarta. The following day Rudi informed me that the doctor had prescribed a TB test and some medicines to treat opportunistic infections.

\(^{64}\) Kaposi sarcoma is ‘a cancer that causes patches of abnormal tissue to grow under the skin, in the lining of the mouth, nose, and throat or in other organs’ (http://www.nlm.nih.gov/medlineplus/kaposissarcoma.html) (accessed 31 August 2011).
About two weeks later I heard that Chandra had been admitted to Dharmais hospital. His mother, his wife Yuni, and his younger brother were in the room when I visited him. Chandra tried to sit up in bed with his brother’s help; he looked pale and thin, and stared blankly at me. His left arm was shaking when he raised it. An infuser was attached to his left hand and a nasogastric tube to his nose. He did not say a word. Yuni said that the family had not known that Chandra was HIV-positive; they only found out in the hospital when the nurse told them. Yuni asked, ‘Why didn’t Rudi and other people at Pantura tell us about the disease? Are they afraid we will be shocked? If we knew from the start, we could have done better to help him’. She told me that if Chandra’s friends at Pantura Plus knew, there should be no more secrecy. ‘But why don’t they tell the family? If he died, wouldn’t they regret it?’ she asked. In a week in the hospital, she saw and learned more about HIV/AIDS from the family members of other patients. Yuni sounded optimistic that her husband would recover; she had seen patients in the room recover after suffering severe illness like Chandra.

Five weeks after being hospitalized, Chandra was back at home. Rudi told me that Chandra’s family had spent tens of millions of rupiah for medical and other costs since they had no health insurance. He looked better when I visited him at the end of March 2007, though he walked slowly and was still thin. The black botches on his face and arms had disappeared. His hand trembled as he poured water into a glass. He said the doctor had prescribed nine kinds of medicine and that he had to see the doctor the following week. I was in Amsterdam when I heard the news that Chandra had passed away in September 2007. Rudi told me that Chandra had fallen ill again and had been admitted to Dharmais for a month. His parents could not afford the medical costs and had to apply for SKTM65 to obtain benefits from Askeskin66 for free healthcare at public hospitals. Chandra’s case shows how his family provided emotional and social support, although they only learnt his HIV status indirectly when he became severely ill. His family did not shun

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65 SKTM (Surat Keterangan Tidak Mampu) is a letter certifying that the bearer is poor. SKTM is formally released by the village head and is legitimized by the subdistrict head.
66 Askeskin (Asuransi Kesehatan untuk orang Miskin) is health insurance for the poor. A patient must have SKTM to obtain benefits from this insurance when he/she needs free health services at a public hospital.
him as he had feared. With such positive support from his family, Chandra’s story could have been different if he had disclosed his HIV status from the very beginning.

**Fragmented healthcare**

Atma and Chandra’s deaths were preventable – testimonials to the fragmented healthcare system for HIV/AIDS. Why did Chandra have to go to the hospital in Jakarta? Why could Atma not use the Gakin card for a second time? In theory, Karawang’s public district hospital has the capacity to handle AIDS patients; some of its doctors have been trained at the provincial level for this purpose. Nevertheless, doctors there felt they lacked experience to adequately treat AIDS patients. As I discussed in Chapter 2, the local government’s response to the epidemic has been hampered by lack of commitment, inconsistencies in policy implementation, and lack of coordination among related institutions.

NGOs such as Pantura Plus and Klinik Kita are crucial in this resource-poor setting as they provide care, support, and treatment. Nevertheless, NGOs have their limitations. First of all, they rely on international funding. They make ARV medicines available, but without regular doctors to monitor adherence; they recruit Odha as outreach workers but are unable to care for all of their needs. NGOs also facilitate support groups for Odha, known as KDS (*kelompok dampingan sebaya* or peer support groups). These groups meet irregularly for members to share their experiences of illness, ARV therapy, drug addiction, disclosure, and encounters with the health services. Doctors sometimes join in, providing information on HIV/AIDS and possible treatments. When asked what benefits they derive from these support groups, most Odha refer to the knowledge they gain. They also felt that, to a certain extent, meeting others in the same predicament fostered a collective identity among them. As Euis said to me, ‘[I have] many friends like this. [I’m] not alone’. Nevertheless, these support groups do not (yet) function as self-help groups.

Mol (2008) states that the broad, ongoing process of care involves bodies, technologies, knowledge, and people – all of which have to interact effectively to achieve the desired result. Care for
Atma, Chandra, and their fellow *Odha* involved healthcare providers, medicines, their families, NGOs, and support groups. Still, the result was often not the desired one. In some cases, families and support groups provided ‘good care’ but the health services lacked capacity; in other cases, support groups helped *Odha* access the health services and healthcare providers did their best to treat them, but the family lacked resources to buy proper food and medicines. In still other cases, healthcare professionals provided good treatment and the family took good care of the patient, but the patient refused to take the medicines due to self-stigma and denial.

The healthcare system for HIV/AIDS in Karawang is fragmented. The public hospital is slow to respond to the treatment needs of *Odha*, the local Health Office has a limited budget for HIV/AIDS prevention and treatment, the local AIDS Commission does not coordinate prevention efforts, the NGOs rely on international funding agencies, support groups remain under the shadow of the NGOs, and most *Odha* live in economic hardship and suffer from self-stigma, limiting their access to health services. These intertwining variables lead to the precarious lives of *Odha*. At the end of the day, many *Odha* are on their own in their daily battle for survival. Many AIDS deaths in Karawang are not officially recorded, which means that they are not counted in the national statistics.\(^67\)

### Conclusion

This chapter has recounted the ‘deep illness’ narratives of four *Odha*. Most combined Frank’s ‘quest’ and ‘chaos’ narratives – the latter dramatically ending in death for Atma and Chandra. Their narratives revealed the dynamics of stigma and disclosure in daily life, and how illness relates to economic hardship. We further saw the tactics *Odha* use to cope with economic hardship, such as sharing food and living arrangements and making use of their social networks.

\(^{67}\) *Odha* who die at home are not recorded as having died of AIDS-related diseases. Most *Odha* learn their status through the VCT services of NGOs, which report all cases to the KPAD and *Dinas Kesehatan*.
Although self-stigma was salient, it sometimes lost its power through disclosure. Disclosure to family members did not always result in stigmatization, as many Odha feared. Some cases revealed the significant roles played by family members and support groups in caring for Odha who had fallen ill. Nevertheless, the fragmented healthcare system in Karawang continued to lead to premature and preventable deaths.