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TOP Support Group Members: HIV Trajectories and Interpretations

It is interesting to see how the HIV positive women I met with who were involved in the TOP Support group understood HIV/AIDS. They were socially and economically vulnerable, both in their families and the community. They were poor and powerless, and lived in an environment which made them peculiarly vulnerable to HIV infection. Most of them found out their status when their child or husband had become sick or died, yet when they found out almost none of the women had yet reached the stage of suffering from full-blown AIDS. Consequently, they did not respond to HIV as a disease; rather, their response was strongly influenced by their bio-social identity as mothers.

In this chapter I describe how the seropositive women engaged in TOP Support; how TOP Support as an organization supports its member; how the women responded to HIV; and what kind of treatment they chose to live with HIV/AIDS.

6.A Getting into the Support Group

Almost all of the TOP Support members were referred by the referral hospitals or by NGOs; only one or two members were found through the mobile VCT service run by YPI in the community. This shows that it is not easy to get people who

have been diagnosed with HIV through the mobile VCT service to become involved in a support group. This is mostly because of stigma and discrimination. If a woman is found to have HIV during the mobile VCT program in her community and she comes regularly to the support group, even though the location is quite far from her neighbourhood, the neighbours will be suspicious. In Indonesian communities, the interpersonal bonds at the neighbourhood level are still relatively high. Thus neighbours may recognize if a woman has been detected as HIV positive, and not only she but also her family will be stigmatized. Additionally, of course, few HIV positive women are found through the mobile VCT service because HIV prevalence is still relatively low.

Members who participate in TOP Support join after finding out that they are HIV positive. Some people had the test at a VCT clinic at a referral hospital. The hospital then referred them to YPI, which not only has a PMTCT program for pregnant women, but also a referral clinic appointed to distribute antiretroviral medications (ARVs) and other programs for people living with HIV/AIDS (PLWHA), including (free) CD4 testing for viral load, PCR tests for babies (also for viral load), etc. Through the PMTCT program, YPI provides recommendations for pregnant seropositive women to deliver by caesarean section at the referral hospitals, an assistant who can remind them to take their medicines, and formula milk for babies for one year.

It is interesting to know that most of the HIV positive women did not know about their husbands' high risk behaviours and health condition until they found out their own status. This fits with the picture of Indonesian women as being passive and inactive in relationships with their spouse. Although premarital medical check-ups are encouraged for couples, and should ideally be done six months before the wedding, premarital counselling and HIV testing are not mandatory due to a lack of public awareness about the importance of such check-ups, cultural influences, and religious dogma that the choice of a spouse should be left in God's hands; going for premarital health screenings questions God's omniscience (Kompas, 2002a; Kompas, 2002b). In addition, a premarital test, including a rapid test for HIV, is relatively expensive; from approximately 800,000 IDR up to 1.5 million IDR²². A survey administered by drug addiction clinics in 2002 found that injecting drug users (IDUs) who have HIV/AIDS have a tendency to keep their status secret and do not dare tell the result of the test to their spouse, even though they still have a sexual relationship with them without using protection (Kompas, 2002c).

The majority of the women in TOP Support who found out that they were infected with HIV after their child or husband became ill or died had not, at the time of this study, yet reached the stage of AIDS. Thus, they had not yet experienced

22 Equivalent to US\$ 91.20-171 (as US\$/IDR= 8,800 IDR in January 2011)

serious symptoms. They were participating in TOP Support because they had been referred by the doctor who handled their ill husband or child. In general, they felt healthy and did not have any health problems.

Wiwid is the eldest among three siblings. She is a little bit shy. She was dating a boy, though because he was living outside of town, so she fell in love with his best friend, who then became her husband. Her husband was an IDU, but Wiwid had no clue about his background when they got married. Two years of marriage passed, and Wiwid happily gave birth to a son. Within one month, however, her son fell ill. The first symptom was fungus in his mouth, then an unstoppable cough. After a few medications, his condition was worsened by chronic diarrhoea. He kept losing weight. At that point he was referred to one of the referral hospitals where he got tested. Wiwid was shocked when she was told that her baby was infected with HIV. The doctor suggested that she and her husband should be tested. The result showed that both of them were infected. Four months later, in August 2006, her son died.

Wiwid started to investigate her husband's background, and discovered that he was an IDU who had been expelled from his family a long time ago. Some of his friends had already known that he was HIV positive. According to Wiwid, his family would not admit it, though they had also known about the situation. Just before they got married, her husband worked in a factory for *Susu Bendera* (Frisian Flag Milk). One day, the factory conducted a medical check-up for workers, after which he was sacked. Wiwid did not know the reason why; she guessed that it was because of his chronic coughing, caused by too much smoking. This was early in their first year of marriage.

Wiwid met YPI staff during their hospital visit, where she was introduced to TOP Support. A few months after her son died, Wiwid joined the group. At the time of interview, Wiwid was not on treatment, though in 2008 she did start antiretroviral treatment (ART) after she got a severe infection in her womb.

I first got to know Mbak Sun and Mbak Ati (YPI staff) at Pasar Rebo Hospital (the hospital where her son had been treated). I've just been active (at TOP Support) for a couple of months, after my child died at the end of July or beginning of August (2006). I just knew about my HIV status a couple of months ago, three months ago, in May 2006. It began from my child, my child was diagnosed positive. My husband and I were also tested last May. The symptoms were diarrhoea, he (wiwid's child) was hospitalized almost every week, until he was almost four months old, but before four months he had coughed continuously. I took him to *tumbuh kembang* (paediatrician), the one they say is the most expensive, but still he was not cured. The cough's gone, the diarrhoea comes. Within a week, he lost around 800 grams

to one kg. I was so concerned what kind of disease he had since he got thinner and thinner. He was one and a half month in the hospital before he died. He was beautiful and active; the nurses said he's got a very high spirit of life. He was not in the coma at that time. I felt so pity about him. That's why we, the family, prayed to God that if he was to be cured, please cure him fast; if not, we let him go. He was 3.3 (kg) when he was born, healthy, his body was normal. I never imagined after a few months he died. Maybe it was my fault. Actually if a child's positive, he can't be breastfed, can't be mixed, if you want to give breast milk, give only breast milk. I gave both breast and formula milk, I didn't know, because all my mother's children got them and because I was working. I didn't know why my breast milk was very little but as a mother I wanted to give the best for him. I thought he would get the body immunity from the breast milk and food from the formula milk. In the beginning, my nipples were wounded, very much until they bled, my child sucked very hard, he was very strong. That's why I thought it's from the breast milk because my nipples were badly wounded and bled and he had fungus in his mouth when he was a month old. There were a lot, until before he died he was resistant to the medicine. Just before starting with the second line whose medicines we don't have here, he died. Moreover, I didn't know about that, usually when a baby gets mixed milk, he'll get solid food by four months, I did that too, that was wrong, I shouldn't have given solid food (for an HIV positive baby). I was stupid; I want to make it better. I know now. I am a hundred times more careful. I'm angry with the one who has infected us. He didn't tell me about that, if he did I could have prepared. (Wiwid, 29 years, married)

Viona too only realized that she had been infected by her husband when her first child was ill. At that time, she was pregnant with their second child. They used to live in Papua where there is no proper medical service, especially for children with HIV. As her son needed medication, she had to move to Jakarta to live with her in-laws while her husband stayed in Papua. The paediatrician was suspicious that she or her husband was an IDU. Her husband, then, admitted that he was an ex-IDU; he may have infected her and the baby. As soon as she knew that she had HIV, Viona followed the PMTCT program at YPI as advised by the paediatrician who treated her first child. Her second child was healthy and free of HIV; she got a free caesarean section and free formula milk from the PMTCT program. Not long after her third baby was born, her husband died.

I got married when I was twenty-one; I got my first pregnancy eight months after our marriage and then I (was) pregnant continuously till I have

been sterilized after giving birth to the third child. There was a problem when I was pregnant with Daud (the first child); at that time we were still in Sorong (Papua). The doctor said, 'If it stays like this, it will be bad for the baby', because the foetus is under the normal weight, I had to vomit every day, that's why I had to go to the doctor every day. The doctor told us we'd better go to Jakarta because there are more doctors and the facilities are good. In Sorong it is limited, there's only one gynaecologist, the vitamins and food supplements are rare. That's why we came here in the beginning of 2003, when Daud was two months old. His father was in Sorong when he was born, he only took us to Jakarta and came back to Sorong. When Daud was four months, he was ill. It all started there. He was given the first medicine, blue pills. There was no paediatrician, there is one so-called paediatrician, but actually he's not. When he had been ill for almost a month, there was a paediatrician who came to Sorong and he said, 'It's fungus already, not only mouth ulcer', and he was given medicines. He could not eat, only vomited. This doctor is also stupid. You know Candistatin, the medicine for children against fungus, it's normally given in a bottle and if the child is not cured after consuming a bottle, he should have questioned it. In Daud's case, he had to take even more antibiotic. Luckily, when Daud was ill, I always kept the copy of the prescriptions. I kept them. When it was getting worse, he could not drink from the bottle but from the pipette. It took a lot of efforts to feed him, even using a pipette; he still had to throw up. Finally we came back here to Jakarta. When we just arrived at night I had to cry. The doctor at Bekasi was also confused and he said, 'I've tried my best, but it doesn't show any progress but gets worse'. His weight was 6kg when he came to hospital, and became 5.6kg. His condition's worse. Then, with the paediatrician, we had a counselling, then he said, 'I (know) you are an ex-IDU, he maybe (has) HIV infection'. We were messed up at that time. At that time I didn't know that I was pregnant (with the second child). I was very emotional. I had a fight with my husband who must have been infected. 'I wouldn't get infected if it's not from you', I said. I went to Doctor Evy (a paediatrician). My husband told me he used to use drugs, but never as detailed as during the counselling, never. I was crying when I was listening to it, but what can I do now? I was depressed and had a mental breakdown. (Viona, 27 years, widow)

Winta did not know about her husband's HIV status until he was in poor health. Winta dated her husband-to-be for four years before becoming pregnant at fifteen. She never knew he was an IDU, though her family never approved of her relationship with him because they thought he had a bad attitude. Her school performance was worsening, and she dropped out soon after graduating from junior high when

she became pregnant. Winta never told me in detail what she had done in her life, though once she told me that she was about to be trafficked by her neighbour who worked as a prostitute, and later on I knew from her friends that she used to work as a call girl.

Winta knew about her status when her husband became very sick. Doctors suggested to her to get examined. At the time she found out about her HIV status, she was eight months pregnant, and then one month later her husband passed away. She was introduced to the PMTCT program at YPI, though unfortunately, according to Winta, there was no intervention given for her pregnancy. She was not given ARV prophylaxis, support for a caesarean section, or formula milk. It may have been considered too late in her pregnancy. When he was examined, her son was also found to be HIV positive.

At the time when I met her, Winta had a second child from her second husband. For her second child she got a free caesarean section and free formula milk from YPI.

We had been married for a month when my husband was ill in 2004. He was ill for three months but his HIV (status) was unknown yet, I don't know, in my family there's nobody who has this kind of illness, it's from him. I wanted to ask my parents, but I don't talk to them; I wanted to ask the neighbours, but they would talk rubbish; I wanted to ask my husband's family, but they don't care. My family and his family do not care. We were just hugging each other. We had a relationship before getting married for four years, but I never knew he used drugs. When it was getting worse, actually I got recommendation to go for a further check-up, but I never did that, I didn't have money and my husband was only selling mineral water on the street. With our income it's not enough, even for food it's not much, not to mention to pay for the rent. He was ill and couldn't work and I was six months pregnant. When he was ill, I took care of him until it got very much worse. He was ill for one and a half month, I was six months pregnant... The worst was when I was 7-8 months pregnant. We didn't have money to take him to the hospital, we went only to a clinic, but no reaction, and it was a waste of money. I asked money from my husband's family, I asked for help, we were given 100,000 IDR, but I used the money to buy food for a week, we still got 40,000 (IDR). My husband was getting very ill, I took him to the hospital as all the medicines from the clinic were finished. The money wasn't even enough for an ELISA (antibody) test, but there was a kind man, my husband was tested and he paid for him. 'Your husband has HIV', the nurse told me. I was very shocked. 'What...? Don't talk rubbish, my husband's a good man, and he never had free sex!!' I didn't know that he was an IDU. I'm still confused if he was really a drug user, as far as I

knew he had been drinking and taking soft drugs, that's what I knew. 'We can see the result if you don't believe it'. When we saw the result it was really AIDS positive. I was out of breath, unconscious, panic, I don't know who took me, but finally I found myself on the bed in the hospital. My husband was also unconscious; he couldn't do anything else besides lie down. When I was awake around midnight, I tried to accept it. I thought he might have had free sex because I didn't know he did drugs, didn't know about AIDS. Maybe he's had free sex, doing drugs is impossible. I have proof that he's had free sex because when we're dating he taught me many dirty things; that is what I thought. If he's HIV infected, I can accept it, but of course if he's positive, I must be positive and people with AIDS cannot live longer than 2-3 months, I thought about that continuously when I was in the hospital. But life's not your decision, it's God's and I didn't know yet about HIV/AIDS. After two days of being hospitalized, I was examined by the doctor who took care of him. I'm positive, I got even more confused. After thirteen days in the hospital, he was home again and after four days, he passed away. (Winta, 18 years, remarried)

Tiara also came to know her HIV status when her husband was very ill. She had never realized before that her husband had been an IDU long before they were married. After knowing that her husband had AIDS, Tiara and their son, Keenan, were also tested and both of them were infected. When our interview took place, Tiara was living alone with three year old Keenan after her husband had passed away. Shortly before, her CD4 count had dropped very low, but she was refusing to start ART as she was afraid that the side effects of the medication would make her ugly.

My husband usually came to Tangerang because his grandmother's sister lives not far from my house. He came there very often because of his grandmother, he came here very often. I usually left my house for fitness, for class, for college. When I went to fitness, he usually waited for me and asked me to go together, that's the beginning, and we just talked. Until he died, he never knew that he's positive. I told his family and other people not to tell him. Four days before his death, he wasn't allowed to drink, not even a drop of water. They said he couldn't because his stomach was having a problem. He was bleeding when he vomited. He was not given any drink or food. The first time he was hospitalized at the neurology department because he had cramps. We went to neurology. The wife of the neurologist is an internist. She's also there, at *Sulianti Saroso* (referral hospital). He couldn't be given ARVs even though he was ill. Under his lips there was a lot of white stuff. If

I cleaned it in the morning, it came back in the afternoon. In the afternoon when I cleaned him, I cleaned his lips until they were red, not long after that the white colour came back. The CD4 level was twelve. After five days, he got a CT scan. Two days after that, after the CT scan, he seemed to be out of breath, he had another CT scan two days later. It appeared that one of his lungs was broken already. Not good. Only within those eleven days, everything was acute. There wasn't anything in the lungs before, but at that time there was. He even threw up blood. His stomach used to be normal, at that time he had a stomach infection. I was immediately examined, the result was ready in two hours and I was told I was positive. I called my mom. 'Mom, I this, this, and this...etc.' That's it. In August 2005 he died, and during the funeral, I told my Mom, 'Mom, I'm positive, blah, blah, blah. What can I do?' My mom said... 'I told you that'. But she's not angry, I mean knowing the condition, she's not angry. Then she asked, 'Is Keenan tested?' She took him right away to *Budi Asih* (hospital). He's also positive. (Tiara, 22 years, widow)

The cases above are fairly representative of the TOP Support members. Another intriguing story was told by Titi who, together with her husband, found out her status after his third time donating blood to *Palang Merah Indonesia* (PMI - Indonesian Red Cross). Titi's husband was an IDU, but neither Titi nor her husband had ever been seriously ill. Fortunately, their only son is HIV negative.

So, my husband had an itching problem. He thought he had eczema although my parents thought it was influenced by our unborn child. At that time I was pregnant. Then, he went several times to the hospital to see a dermatologist, but it couldn't get better. We thought when the medicine was finished it could get better. Finally, he decided to donate his blood because he's an IDU, he thought he could get rid of the dirty blood by donating it to PMI. We didn't know his status yet. He had been donating three times, and before donating for the fourth time we got a letter from PMI that my husband's blood couldn't be accepted. That was actually the third notice already, but we had only received the letter once. After that he stopped. Then, PMI told us that it was only a screening test. Not..., not everything, not accurate. So in order to get accuracy we were referred to Prof. Zubairi. Finally Prof. Zubairi referred us to *Prodia* (clinic laboratory) for a full HIV test. That's it. After the delivery I was tested. Just after knowing that my husband's positive, at that time I was at Bunda Hospital, I was crying like crazy. And then the Prof. advised me to see Mbak Tika, who later gave me counselling. So I had the counselling right away at the same place. But, at that time I had not dared to have a test. Four months later I had the test. When I knew

that I was positive, I was ok actually. I was ok, I accepted it, I thought there's nothing I could do. Only when I knew for the first time that my husband was positive, I was hysterical. We were both also not ready to let Yanto have the test (at that time). We were finally ready that he could have the test when he was tow years old. (Titi, 24 years, married)

Not all of the seropositive women involved in TOP Support were definitely infected by their spouses. Some had been IDUs themselves, and some were still actively taking drugs when I met them; although some were taking only oral rather than intravenous drugs. These women were often not really sure when and how they had contracted HIV; it may have come from the needle they shared with their husbands or friends who were mostly IDUs, but it may also have come from unprotected sexual intercourse they had when drunk.

Asti was an active girl, and had used drugs from an early age. Her first husband was the best friend of her then boyfriend. Asti did not know that he was an IDU, and she fell in love with him because her then boyfriend, who was of a different religion, dumped her to get married to another girl. Her husband worked as a band member after he quit his previous job as a Blue Bird taxi driver for health reasons. When her husband fell ill, the doctor recommended taking an HIV test, which was how they came to know about his status. Asti wondered whether she had been infected by her husband or the other way around, since both of them used to be IDUs. Asti had a terrible illness just before she had the HIV test, and had begun to suspect that she was infected because her illness was as bad as her husband's. She went to *Puskesmas* Tebet which provides services for IDUs, and from there was referred to YPI.

I started taking pills when I was in Senior High School, then we shared needles. It didn't last a very long time, only for a year and I wasn't addicted, just occasionally. If there was some, I used it, if not, I didn't. My husband didn't know about that, he was shocked. He used drugs occasionally too, but I never saw him taking them. I noticed the difference when he worked as a security guard; he often had fever and muscle pain. I once saw him with a big school bag full of drugs. He had been ill for a long time, at the clinic they always told him he had typhus; I didn't believe he always had typhus, the longer, the worse. We went to a professor; he was advised to eat a lot of *pisang batu* (a special sort of banana) and coffee. I didn't believe it, I told him we'd better go to the hospital. His condition was worse... He ate but was getting weaker; he was shaking when he walked... His body was trembling... Finally I told him to go to the hospital because he's trembling. His mouth was full of fungi. He was hospitalized for twenty-one days and had a therapy in Indramayu in his hometown, the traditional massage in his

hometown. He could walk again; he could even drive, his body was heavier. But I don't believe that. He still consumed ARVs; I took them from the RSPI (referral hospital). Also the traditional medication. He used to weigh 45-65kg; it reached 20kg within seven months. You can imagine...only bones... I wanted to cry seeing him like that. Although he was shaking when he walked, his weight was ok when he died, I was shocked... He was about to have a job promotion. The symptoms were like having a heavy chest and he could not breathe, very heavy. So, when he died he got tuberculosis, was operated. He used drugs, but he was not honest to me, until the end. So, I didn't hate it very much because he knew I was a drug user. I didn't think that way. He was infected by me? Or I was by him? (Asti, 30 years, remarried)

Strikingly, although many women realized that being an IDU made them vulnerable to HIV infection, some still believed that they got the disease from their husbands rather than because of their own risky behaviour. One reason behind this way of thinking could be the fact that these women had never been seriously ill.

Lina's experience with drugs was not very different from Asti. Lina was also an IDU, but she still felt that her husband had infected her because, according to her, her experiences with drugs would not infect her with HIV. Sadly, Lina passed away in May 2009.

I've used it, only three times. Well, actually I just wanted to try it, but maybe I was infected from it. It was only three times in a year. I shared it with my husband. So at that time I only wanted to try it. Just to try it. Actually, with him was twice and with his friend once without him knowing. He actually didn't allow me because he told me that I could get addicted. But I said, 'If you can, why can't I?' I just wanted to feel how it's like, that's why. I used something, what was the name again? For him who was used to having it, it might feel good, but for me I felt different, I felt dizzy, nauseous, light headache, I wanted just to sleep. That's it. It's not that I didn't want to try it anymore but I thought it only felt like this. That's it, maybe I was infected from that because we were married maybe only for a year. If I knew that the needles had that effect, I wouldn't dare to try it. Also with my husband; if he had known, he wouldn't have done it. Only us, it is enough. We've done it, so we deserve it, but why our child is also becoming a victim - that makes me sad. (Lina, 22 years, remarried, passed away in May 2009)

In addition to being referred to TOP Support by the hospital or doctor treating their ill husbands or children, some women found out about the support group when they were hospitalized themselves due to an HIV/AIDS related illness, and

other TOP Support members made visits to the hospital, as in Wanda's case.

Wanda is the second of four children in the family. She was known as the rebel in her family, and had a very bad relationship with her father. Wanda said that there were no members of her family that she could talk to. Her father was a civil servant who earned an extra income by renting houses, which meant that her family was quite prosperous. When her father retired from his job, he began to focus every day on his hobby, fishing, from the evening to late at night. He said it was best to catch fish in the dark, but Wanda thought it was just a good reason to escape from the boredom atmosphere at home. According to Wanda, her father loved her brother and sisters more, especially since her sisters were quiet and obedient. In high school, Wanda started to have a relationship, though she got pregnant by someone else while drunk. She married the father of the child, but then divorced soon after she gave birth. Her first child was not infected with HIV and until today lives with her parents in Pasar Minggu. Wanda married for the second time with her boyfriend. She gave birth to her second child who was luckily also not to be infected.

Wanda told her family that she had been infected with HIV by her husband. None of her family members knew that she used to be an IDU, or that she occasionally smoked marijuana, used heroin, and drank alcohol with friends; though she did stop using drugs when she was carrying her first child. Her husband, on the other hand, was using drugs up until he died, even when he was ill. Wanda had lost hope after she had been in hospital for one year, at which point she met the TOP Support staff who made a hospital visit.

Since the first year of junior high school I have started with smoking weed, I got it from friends. Nobody knew at home. I once got home with red eyes after smoking weed, but because it was at night, my father didn't really notice. That's the only time, usually I didn't do that, and I didn't dare to get home like that and never took the stuff home. I once took the aluminium foil (for heroin) home and put it in my purse; my sister found it and asked, 'What is it for?' 'It's nothing,' I said. I had used it together with my husband, but we didn't know, we thought if we washed it, it would be clean. But actually, it's not simple to clean it, you have to use a bleaching if I'm not mistaken. Three times washing and then with water, that's how you wash it. We used to think to clean it with warm water, but it's wrong, it should be cleaned with cold water, that's why some junkies are dead. Actually, before doing drugs, I knew that I got HIV. Because the doctor told me that my husband was probably HIV positive, I thought I had to be positive too! The doctor told me, told me to check it just in case. But I was scared, impossible, and impossible. I was then hospitalized for the first time, I had feelings already, but I didn't want to admit it. I was healthy again, and then sick again, and was hospitalized

again and again. They said that it might be typhus. The second time I was diagnosed as having typhus. I even took traditional medication, I ate worms which have been first cooked and grilled and chopped. It should be cured, but not in my case. I still had fever, fourthy degrees, I had feelings already. Finally I went to GMC (hospital) at Buncit, I made a confession to a doctor, not to my family; but I told him not to tell my family since it's one's right to have this matter confidential. 'Go ahead tell me', he said. I was crying, scared, I just knew that it's a serious disease, the second killing disease in the world. I thought there's no medicine at all. The doctor told me, there's no medicine for HIV yet, but there's an antivirus to prevent the virus from growing. I was referred by GMC to IRNA RSCM (referral hospital). I was the only female. At RSCM at IRNA I knew I was positive. I think YPI means a lot to me, that (first) visit. When I was found to be HIV positive, I was referred to RSCM. Every time I woke up at that time I was like dreaming whether I was still alive or not. There was a hospital visit. Mbak Yuna, together with Mbak Lina and Mbak Sundari (YPI staff) visited me. My mother didn't want to talk to them. Mbak Sundari said, 'We are friends. These are your friends and I am too'. In the beginning I was wondering what these people were doing since they didn't know me but they visited me. Later they explained to me that they were members of YPI, *Yayasan Pelita Ilmu*. They asked for my phone number. I asked for their name card. From then on I knew that I'm not alone. One who looks very healthy can have it (HIV) too. Then I asked Lina, 'Where were you treated?' '*Alhamdulillah* I've never been ill', she said. I made up my mind I have to be cured. TOP Support means a lot to me. When when I was finished with the treatment, I joined YPI. (Wanda, 27 years, widow)

Dina's story is unique among the women of the support group. She became infected with HIV because she was a drug user, yet her first husband had never been tested. She had three unhealthy children from her first husband; her first and second child had never been tested until they died. After delivering her third child, she became so ill that the doctor advised her to get an HIV test, but when she found out that she was infected, her husband left her. Now, Dina was remarried to another PLWHA who pumps up her life spirit and supports her to continue taking ARVs and together they had another child who luckily was not infected. Unfortunately, Dina passed away in 2010, not long after her second husband died.

I knew I was positive in July 2004, at RSPI (referral hospital), with a counsellor. I was asked to have a blood sample test and three days after that I had another counselling. I didn't know that it was HIV, but my father knew. After delivering my third child, I was sick. Since her birth until the fourth month, I was never healthy, sick, thin, having fever, and my hair fell out. I thought I had a hernia. I got a massage and went to the doctor, but I wasn't getting better. My father asked his friend who worked at the clinic of the office where he worked at and also at the RSPI. He said to him, 'My child's been ill for four months but why is she not getting better? Her first child died, the second child's also ill, both of them have a lung disease/What are the symptoms of her illness?/Fever, her body's very thin, her hair's falling out/Did she use (drugs)?/Yes, she used injection drugs/Let her have a blood test done, maybe she has HIV'. Father said to me, 'Go get a blood test done'. When I was checked I was asked what the symptoms were. I said, 'I'm ill, coughing'. The doctor said, 'Oh ok, do you want to have a blood test? You'll talk to the counsellor'. He meant that I should have the counselling first and then followed by a test. (Dina, 23 years, remarried, passed away in 2010)

6.B. Advantages of Being a Member of TOP Support

Nowadays, there are more people with HIV/AIDS getting actively involved in HIV prevention programs. It reflects what Nguyen has classified as the second flow of HIV intervention programs, that sees the involvement of affected communities and local forms of solidarity, with the concepts of buddies, self-help, and empowerment (Nguyen, 2005, p. 127). The GIPA (Greater Involvement of People Living with HIV/AIDS) spirit has influenced them. The number of support groups is increasing all over Indonesia. In 2006, there were ninety peer support groups for PLWHA located in fifty districts and cities in twenty-six provinces across the country. In June 2007, according to data collected by *Yayasan Spiritia* (Spiritia Foundation - an NGO which is actively involved in HIV prevention programs), there were 161 peer support groups spread all over Indonesia, most of them located in Java Island. Those groups supported specific target groups including transvestites, homosexuals, methadone consumers, injecting drug users, women, uninfected partners of PLWHA, families, and outreach workers. Of the 161 support groups, the majority targeted IDUs, and there were only ten which especially targeted female PLWHA.

Figure 1:
Support Groups for PLWHA in Indonesia, June 2007



Source: *Spiritia* Foundation (Spiritia)

In Jakarta, there are twenty-seven known support groups, only two of which are specifically for women, including TOP Support created by YPI. This low number is understandable as not many seropositive women are registered or recognized by NGOs or the government. According to the National Coordinator of *Ikatan Perempuan Positif Indonesia*, the Indonesian Positive Women Affiliation, they supported 250 seropositive women in 2008; those women were IDUs or partners of IDUs, sex workers, or partner of sex workers' clients. Although the number of seropositive women does not seem like much according to the statistical data, it has been increasing significantly in recent years.

YPI has been running a program of care and support for PLWHA in Jakarta since 1994. Up to December 2003, YPI had provided care and support for 669 PLWHA. However, to strengthen their HIV/AIDS prevention efforts, and due to the increasing number of PLWHA and the expression of the GIPA (Greater Involvement of PLWHA) spirit, the support group *Pelita Plus* was set up in September 2002, whose objective was to increase PLWHA's quality of life. *Pelita Plus* was a mixed support group open to seropositive men and women. YPI supported them with a room for an office and equipment, and at the beginning also empowered the group with organizational skills and self esteem; *Pelita Plus*, however, conducted its own activities. These activities included a monthly meeting for PLWHA, home visits, hospital visits, public awareness and community campaigns, and income generating activities such as creating products for sale (t-shirts, postcards, red ribbons, dolls, etc.). One of the public activities of *Pelita Plus* was to advocate for the government to provide ART

access in Indonesia. *Pelita Plus* organized a street rally with 200 participants and declared the need for ARVs in 2004 (Habsyi, Yogatama, & Muhaimin, 2004). Due to a mismanagement matter, *Pelita Plus* is now inactive.

As a sub-group of *Pelita Plus*, YPI established a support group especially for seropositive mothers in Jakarta as part of their PMTCT continuum of care program to provide psychosocial support for seropositive mothers, their babies, and their families as written in the prong 4, that is to provide psychological and social support and treatment to HIV positive mothers, their babies, and their families. It started with six seropositive mothers in August 2005. The group, called TOP Support, derives its name from the abbreviation of *Tim ODHA Perempuan*, which means 'seropositive women's support group'. From its small beginnings it grew to fifty women in 2009. The role of TOP Support is to provide psychosocial support to seropositive women and to advocate for PMTCT to the wider community. As a support group, it provides a comfortable space to make it easier for seropositive mothers to disclose their HIV status and share their problems with other women like themselves. The bio- social identity of motherhood is very significant for TOP Support members. TOP Support also has a role as an advocacy and interest group that consists of women who have a condition and who have something to gain or lose from the group's actions (Kitsuse & Spector, 1995).

Using the funds from Global Fund in 1999-2001 for the PMTCT program, YPI supported seropositive mothers mainly by providing a service for caesarean sections in conjunction with some referral hospitals in Jakarta, offering recommendations to get ARVs²³, and providing formula milk for newborn babies in their first year. During the first years of the PMTCT program in 1999-2001, YPI provided a caesarean service for eleven mothers, nine received ARV treatment, and six babies were provided with formula milk. Between 2003 and December 2005, YPI continued its PMTCT program using money from the Global Fund. Twenty-eight women had assistance for a caesarean section to deliver their babies.

The PMTCT program performed by YPI has depended much on donor support. As a result, not all seropositive mothers who join TOP Support can access the caesarean service, and some activities can only be carried out irregularly when YPI manages to get extra funds, for example PCR (Polymerasi Chain Reaction) tests for babies, CD4 tests, and income generating activities. Through TOP Support, YPI has provided HIV positive mothers and babies with psychosocial support from buddies, hospital visits, and home visits. YPI allows TOP Support to use one of their office rooms for their secretariat and weekly meetings. Two days per week, either on Wednesday or Friday, two people are in charge of the secretariat. They receive money to distribute

23 Without a recommendation letter from a doctor, clinic, or NGO, it is impossible for a PLWHA to get ARVs for free.

as a transportation fee of up to 25,000 IDR to each woman who attends the group meetings, with an additional allowance if they go for home or hospital visits.

The help provided by YPI through its PMTCT program, especially the medical help which would otherwise be costly for TOP Support members, has been very useful for the seropositive mothers, as described by Lina below:

...(it was) from the PMTCT program, so every woman who gathered there got the CD4 test for free. There was a program (free test from the YPI), everybody was asked to have the test done, but every six months. I used to have the test done myself. In the beginning I had the test done every six months, and then I got it free from here. If it's free, it's only once a year here, and only at the end of December. It's been four times. In February 2005 was the first time, the second one was three months after that. The first one was 260, at that first time CD4 count was tested. The second one was 337 or something like that, oh yes 337, two months after the first test, no, no, three months. Then, the 400-something was in the month, the month before this, before the 146 one. In March 2006 it was 146 and I was put on medicine. In December, if I'm not mistaken, it was 438, it was from YPI (her CD4 count increased after the medication). I paid the tests myself, twice, eh once in April. The rest was from YPI. In February, the first time, was from *Kampung Bali*. In December was also from YPI. In March it was from the PMTCT program. The ones from YPI were free. Only once, the one whose result was 300-something, 337, that's the one I paid, 110,000 IDR, at the Dharmais. I get the Duviral from a clinic, the *Remaja* Clinic, I only paid for the doctor, (which) cost 15,000 (IDR). The ART is free of charge, from YPI. (Lina, 22 years, remarried, passed away in May 2009)

Because a caesarean section is costly and the funds are limited, YPI can only provide three per month, and a limit is set to only one caesarean section per woman. Thus YPI states that they will not provide a caesarean section for a woman if she has had the service before. However, they do make exceptions in some cases, and YPI has helped women with their second caesarean section, as Viona discusses below. She received a free caesarean for her second child and had to pay only fifty percent of the cost of the caesarean for her third child.

Doctor Evi called and asked me to come to have the test at Cipto (referral hospital). There was a representative from YPI, it was Mbak Tia. I had a (free) c-section with my second child, and with Joshua (the third child) I got help for half of it, I paid the other half because his father had a job at that time. And (formula) milk. But I had to pay for the prophylaxis. Now I have to buy

one kind of ARV. For Daud (her first child, HIV positive) I have to buy one kind too. Only Reviral, he only has to take one kind (of medicine), I have to pay 200 (200.000 IDR). A counselling costs 40,000 (IDR), I have to pay by myself. (Viona, 27 years, widow)

When the funds provided are not enough, YPI refer patients to get treatment at a hospital or clinic that has similar facilities and services. For example, Dina was referred for a free caesarean section from RSCM Hospital and a free check-up from Dharmais Hospital. Actually, Dina was under medication by the RSPI Hospital and referred to YPI to get the caesarean through their PMTCT program, which is when she was registered as a TOP Support member. She gets free ARVs from RSPI hospital but for her opportunistic infections she has to pay for the medicine herself, which is relatively expensive.

In total, it costs 6,700,000 (IDR). YPI provided 5,000,000 (IDR). I delivered the baby at RSCM. Before giving birth, I got a training from YPI, the PMTCT program. Babies born to mothers who have HIV get ARVs until six months of age in RSCM while it is given only for a week in RSPI as stated in the national guidelines. So, I went to RSCM as well as my baby. It was in December. I was checked two times, the first one at Dharmais (referral hospital), it was free of charge. When I had the CD4 test on June 13, it was free of charge, at Dharmais, as well as the one I had in July, also at Dharmais. It actually costs 110,000 (IDR for the CD4 test), but I didn't pay anything. It (the test) is also free of charge for my child. (Dina, 23 years, remarried, passed away in 2010)

As mentioned above, aside from the medical service, TOP Support members also receive a transportation fee of as much as 25,000 IDR each time they come to YPI to do administration work or for hospital/home visits. The amount may not be much, but it can help their financial situation since most of them do not have a regular income. The most significant benefit of their participation in TOP Support, however, is that they realize that they can again function socially like other women who are not HIV positive. By taking ARVs, they hope to live longer, as explained by Tiara below.

Luckily it exists, so I know, I'm not as afraid as in the past, like I thought I would just die. Now, I'm like, 'Hmm, why should I be afraid, there's ARVs...' That's it, maybe not as long as other people, but hmm... It's ok. The (weekly) meeting, it makes us understand more, to learn, a lot of benefits... (Tiara, 22 years, widow)

Their involvement in TOP Support enables them to have a chance to have contact with other people, to learn from their peers, and to support each other. Sometimes TOP Support has a gathering activity where they also invite members of other support groups. Through this, the women have a chance to get remarried and still have healthy children. Most of the seropositive women I interviewed were still sexually active with their partners; some of them were unmarried and had multiple partners. In most cases, they had met their new partner(s) at the TOP Support activities in which they mixed with people from other support groups. Although those who have had experience with an infected child are usually afraid to have more children, the chance to have a healthy child makes them feel like normal women again. This motivates most of the women to want to have children. Having a child is also a support for them to stay positive about the future.

Dina's story below shows how she got a new spirit of hope after she remarried and delivered a healthy child with the assistance of the PMTCT program. Dina and her first husband had three children who all died when they were still babies. When the third child was ill at the age of four months, Dina and the child were tested. The results showed that they were both positive. Dina was at that time very sick, but the child passed away when she was only ten months old. Dina has since met her second husband, who has given her a spirit to live. They now have a healthy baby. She even wants to have another baby after giving birth to her healthy fourth child.

I took Neviral Duviral in 2004, I quit for a while because I was lazy. My child passed away. After she passed away, my husband wanted a divorce, and then I got HIV, I didn't know if I had friends. I thought I just wanted to die. Luckily I'm not dead yet. If I were not visited (by her second husband) maybe if it was later, a month later, and a week later, I would have been dead. Worse, got mouth ulcers, couldn't talk, my mouth was dry. I went back to the doctor and told him, 'Doc, I want to take medicine again/Are you serious now because if later the drug regimen has to be changed, it's not available yet in Indonesia', he said. 'Yes, I'm now serious, I'll be obedient, I used to have many things in my mind'. And then I was given it, I should try Neviral Duviral first. I started again in May 2005. Yes, if we have the spirit. The PLWHA also need the spirit besides ARVs. If I fall in love, it increases, I gain weight. Feeling good, happy feeling, having a lot of friends. My second child died four months old; the third died at the age of ten months. I didn't know it by the first child, the status of the third child was known. The second child died earlier before having the test. The third child was tested when she was four months old, positive, always sick. The fourth one has been tested, negative. If I knew, I would have already cured it. I breastfed, had a normal delivery. Her food was like the normal babies. When she was 4 months old she was sick, I'm too, and

that's it. I didn't understand. All of them were born normally, only the last one with c-section. After knowing it, I want to be pregnant again, to have offspring. (Dina, 23 years, remarried, passed away in 2010)

Dina is not the only member who has found her partner at the activities of different support groups. Lina, Yuna, Asti, Vina, Tiara, and Wiwid have all had relationships with other PLWHA. Some eventually married. By functioning socially by getting married and having children as most mothers do, the members of TOP Support can minimize the stigma and discrimination against them.

6.C. Who are the Members?

TOP Support members are young HIV positive mothers. When the data was collected in 2005-2006, the youngest TOP Support member was eighteen and the oldest thirty-six, though most members were between 22-29 years. Most are referred by referral hospitals and NGO clinics. They are living in different places in Jakarta, and 6 members come from outside Jakarta in Bekasi, Depok, Tangerang. Some of them, especially those living further away, complained about the transportation cost to come to the weekly meeting, which is quite expensive.

The members of the support group have many things in common. At the weekly meetings, they discuss their common problems, such as getting infected by their husbands, pregnancy and labour problems, being widows, having children with no fathers, etc. Some of them had HIV positive children and husbands who had passed away at the time of data collecting. Female PLWHA have more problems than just HIV/AIDS and their general health. They have economic problems; some because their husbands are jobless and spend their little money to have sex with other women or buy drugs; some do not have good relationships with their families or in-laws; some are married without permission from their parents so they do not have access to financial help from them; some come from very poor families. Although the cost of ARVs is not one of the problems (because they can get them for free from the referral hospital), the transport costs to collect the medication is an unsolved problem.

Most TOP Support members do not have a good enough educational background to get a decent job; only some could continue their education to get a diploma, and while most of them had been to senior high school, not all were able to finish their education due to problems related to drug use or teenage pregnancies. Some did not even finish junior high school. For those who were using intravenous drugs during school time, they did not study seriously.

Wanda moved schools a lot when she was in elementary school because she

was badly behaved and often missed classes. She was not allowed to hang around and play with friends at home so she skipped school to play with her friends. She started smoking when she was in the third grade of elementary school and started using drugs in high school. Currently, Wanda is unemployed.

I changed junior high school three times because I was naughty. At home, my dad always controlled what I did, even when it was right, let alone when it was wrong. For example, I had to be home by 1pm after school. We never know sometimes you have to stay at school for extra lessons or extracurricular activities, he doesn't care, I had to be home at 1pm and I had to stay at home, could not go anywhere else. That's why the time to go to school was used to play; I skipped school often and moved to another school. First, I moved to a public SMP (junior high school) at Srengseng Sawah, then to Islamic public school SMP Tsanawiyah Negeri. Later on, because I skipped school very often, I moved to SMP Pasar Minggu, close to Ramayana department store Pasar Minggu, but my habit didn't change. Then I moved to Kalibata, next to the army cemetery. I was dropped out of school and asked to find another school. They couldn't accept me at school if I kept continuing skipping classes and getting bad grades as a result. That was my last school, SMP Kalibata, a private school. After that I really wanted to get into a SMIP (Senior High School for Tourism), wanted to take a hotel school, I wasn't allowed, I even had two tests. At SMIP, I passed the test for the height and weight, I just needed to do another test, but I wasn't allowed. It's a waste of money to have bought the application form. I looked for another SMA (senior high school) and found an SMA at Borobudur, Cilandak. The school began in the afternoon that made me even worse. I was very bad if it came to school. It's because my father didn't want to understand what I wanted, never on the same page, also the other family members didn't care what I wanted. For example when I wanted to join the basketball extracurricular activity, my father thought it's strange, what I should do with a ball? Another example, if I entered SMIP, I would continue my study at *Sahid* University (a well-known university for tourism), but I wasn't allowed!! See what happened, I moved from Borobudur to a SMEA (Senior High School for Economy) at Tanjung Barat area, I didn't finish it, I paid to get the illegal diploma. I started with it (drugs), I tried it since SMP. I was depressed, nobody understood me at home. At home they were all silent. (Wanda, 27 years, widow)

Asti's story is not much different from Wanda's. Asti became an IDU in senior high school. She moved from one school to another as she was expelled; she was even moved to another province where she went to a Catholic school. After four years

of her relationship, she had to marry her boyfriend when she was seven months pregnant.

My primary school was in Jakarta. But because of my attitude, since I was at the primary school in South Jakarta I was known as naughty because I smoked, was boyish, didn't like girl's stuff, I played cards, skipping ropes, flies, and I did fight with other schools. That made my mother worried. When I finished my primary school, my mom sent me to the village to continue my junior high school. A Catholic school in Boyolali. When I was in junior high school, I still used to fight, very often. My weight was only 20 kg or something like that, very small, that's why I used to be called 'tiny Asti'. I used to come home late, my aunt found it difficult to take care of me. I used to date a Christian guy for six years, until we went to senior high school. He's a motor racer. He was alone there. His parents were in Kediri. I almost got married to this boy, but my mom didn't agree because we had different religions. I chose my parents of course. I went back to my mom and did my senior high school at SMEA (Senior High School for Economy) YPK in Jakarta, at South Manggarai. I dated another boy for four years, then got married, at the age of twenty-two, eight years ago, I got married by accident (because she got pregnant before she was married). I delivered just two months after our wedding. (Asti, 30 years, remarried)

Those who were not IDUs usually dropped out of school in order to get married, as they had become pregnant out of marriage. In Indonesia, women who are pregnant cannot get access to continue their studies, even at the basic or high school level. However, very few Indonesian women who are married and have children want to continue their studies at the university level because they lack the time, on account of being mothers and housewives. Winta told her story about her problems related to her teenage pregnancy.

My primary school was at Bukit Duri, I always had good grades from my first until sixth year, was the second or third rank (in the class). My father was very happy to see his child doing well at school; I was very much loved by my family. When I entered junior high school, the first year, I started to date. At fifteen I was pregnant, but at that time I entered the first year of senior high school already and I stopped. I wasn't expelled from school, I just stopped. In my first year of junior high school, I started dating my husband who died lately. I dated him. I was twelve; he had finished his senior high school. I didn't want to listen to my parents that I must not date him. I just said yes. We lived in the same neighbourhood, so my father knew his daily life and he didn't

like him. But we still dated that my father had to slap me. He had never done it before; he slapped me with his hands, later on with things, broom, and stick. Even the stick didn't make me scared. Then *sapu lidi* (another form of broom to clean usually hard surfaces, contains of a lot of pieces, each piece is made of thin wood), but it still didn't make me stop. Then with rubber, he slapped me with rubber, finally he used electric wires when we had dated for three years, at that time I was in the third year of my junior high school. At that time I was still a virgin; when I graduated from junior high school my boyfriend took my virginity. My father became angrier...!! When I was pregnant my father was even angrier. I was fifteen years, got married to my husband. After getting married my husband was ill and my family didn't want to accept it and we ran away. (Winta, 18 years, remarried)

From the above descriptions, one can see that the school environment does not always have a positive influence on students. These women did not go to school for the sake of schooling, but because it is the norm. They did not study or take the lessons seriously. The school was even in some cases the location where they were introduced to high risk behaviours for HIV, such as sex and drugs use.

With limited education, many of these women have limited work chances as well. Most of them are unemployed. Even those who continued their studies to a higher level do not have jobs. However, as women, they are not regarded as the main earner in the family, and therefore they do not have an obligation to get or maintain a stable job, even though there may be no fixed income in the family if their husbands are also jobless or have passed away. Even if they do have jobs, they only have limited choices, such as unsecured jobs that do not require special skills, and they may change jobs frequently.

While waiting for her high school certificate to be given, Asti got a job as a sales promotion girl, but she quit since she was bullied by her seniors. Then she got a job at California Fried Chicken. She had problems with the manager who did not give her a free day to hold a birthday party for her first daughter. Asti quit the job and has not had another job since. Instead, she helps with her mother-in-law's house renting business, and she and her friends try to run a beauty salon, whose customers are *dangdut* singers (local performers) and prostitutes at Tanjung Priok, North Jakarta. Right now, she works as a peer educator in one of the NGOs concerned with HIV/AIDS.

I started to work as soon as I finished high school. I hadn't had the diploma yet when I applied at Matahari (a department store) at Jatinegara Plaza (a shopping mall in Jakarta), as a sales assistant, (it was) only for a month, because there was a problem... I was new. I think it was because of

the old sales assistant ... She let me take care of the counter while I was still having my probation period, I didn't understand yet. There was a problem at the cashier desk; the customer was angry because the alarm on the port went on and that the security guard had to come, while the customer had paid for the purchase, I didn't understand yet. That was it. Instantly there was a problem. So, my uncle had a job for me at a cooperation, a credit cooperation, bookkeeping, it was ok. I worked there...for seven months. In short, I finished my high school, a month at Matahari (department store), then seven months at the credit cooperation, and then at California Fried Chicken for two years at Tebet, then changed to Mc Donald's for two years. I keep changing (jobs). I used to be a dancer, a modern band, when the Batavia dance was in I used to dance at hotels, it's not bad. I used to work at California (Fried Chicken) as a cashier, a door girl, cook; I have done all of them. But, I had a problem with the manager. It was because I couldn't get a free day for my daughter's birthday. I now work in a salon, it belongs to my friend. Most of them (the customers) are the girls (prostitutes), they have (hair) bonding treatment. (Asti, 30 years, remarried)

Wiwid used to have a successful tailoring business. But then she ran out of capital when she used it all to pay for her baby's medication, which was quite expensive. Her employees resigned, one by one. Now, Wiwid is trying to build up her future again, and received quite a few orders for the last Eid at the time I spoke with her.

I still have my own business; I have to keep good relations... Now, my business is getting better, when they knew I had started again, they were interested to contact me. Actually, it was not really bankrupt, it was just because I couldn't handle it, and without me they couldn't make any move. Automatically, there were no orders because we were not available; I had to stop (working) because I took care of my children. I was pregnant, so I had to take it easy; some of the employees got married. Only one stays with me, she's like a family member, her house is also close. Some other employees just quit. (Wiwid, 29 years, married)

Without a proper education that would enable them to get decent jobs, these women's lives rely very much on their families, especially to cover their medication expenses and childcare. Most TOP Support members live with their parents or parents-in-law, and thus their expenses are the burden of their extended families. Naisbitt (1996) points out that in a country lacking a formal social security system such as Indonesia, the extended family is an alternative safety net for people. Vina told me that her life is at the expense of her extended family.

My mother told me that she used to take care of me the first time they knew that I was sick. She used to remind me whether I had taken my medicine or not. I am worried that I'll be tired of taking medicines. I also have difficult problems that I cannot solve. My brother is now working, (but) I'm afraid that he cannot work anymore. He gives money to us every month. If he doesn't work, how can I get money for daily expenses? I don't want to use my parents' money. As long as I am a PLWHA, as long as I have hopes, I still want to use my own money. *Alhamdulillah*, I can pay for my child's education and other expenses. I also don't ask for transportation costs from my parents. My brother works at Garuda (an Indonesian airline). (Vina, 29 years, widow)

Asti and Viona told me that their in-laws financially support them with their living expenses. Their in-laws support them because they realize that it was their sons – the women's husbands – who brought the infection upon them, and therefore the in-laws should be responsible for them.

When my husband was sick, it was only my parents-in-law who knew about it. Also the first time we got a test, I only told my in-laws. So, my parents didn't know about that. They didn't know about it until I was sick. First, I went to *Cipto* (HIV referral hospital), to *Pokdisus* (HIV Integrated Post) precisely, so my mother knew that I got this disease. Now she can accept it. The support, any kind of help I need to get cured, I get it from my mother-in-law. Even for our business, like to lend some stuff (some credit), as long as we can have a job. For the rent, we're also given (that). I now live in a rent house; it belongs to my parents-in-law. My family doesn't know about it, but my parents-in-law do. I don't talk too much to my own mother, the reason is because my mother thinks too much about her own children, and she takes care of her grandchildren, so it's impossible to tell her. She knows that my disease will get worse, but she only gives me (mental) support. My younger brother knows more than her. My younger sister just knew about it from my mother because there was a problem when I was taking Neviral. About my child, I rely on my mother and mother-in-law; they know better. Right now I'm living the rest of my life positively. (Asti, 30 years, remarried)

My daily expenses and those of my children are taken care of by my parents-in-law, fully. For the medication, my parents-in-law pay. My parents don't know, because my mom, she had a stroke, I'm afraid she'll get worse. (Viona, 27 years, widow)

Because many of the women do not feel that their behaviour might also have put them at risk for contracting HIV/AIDS, most feel that their parents and in-laws should support them if their husband infected them.

6.D. Being Seropositive Women: What They Should Cope With

People are often blamed and stigmatized for their illness and it is a common assumption that individuals are responsible for their own health. When an individual develops AIDS, people assume that he or she was/is either promiscuous, drug addict, or homosexual; and the stigmatization lead others to reject him/her and hold him/her responsible not only for not seeking care but also for becoming ill (Levin, Innis, Carroll, & Bourne, 2000, pp. 278-279). In the minds of many people in Indonesia, HIV/AIDS is associated with criminal behaviour and a hopeless life. Added to the general lack of knowledge about HIV/AIDS, which makes people afraid to be close to an infected person, this creates an atmosphere of fear and accusation around infected and affected persons. There is a social stigma, for example, that HIV/AIDS will only infect 'badly behaved' people. Seropositive women are confronted with multiple stigmas, for not only are they discriminated against as women, but additionally they must face a society that is ignorant and fearful of HIV/AIDS, that looks down upon them because HIV is considered to be the disease of commercial sex workers (Sciortino, 2007), and because they are often the widows of PLWHA. To make it worse, women are sometimes stigmatized and discriminated against by their own families. To avoid this, some seropositive women are not willing to disclose their status, especially to their families. This may become a dilemma for them as disclosure is often required to gain access to treatment and therapy (Waddell & Messri, 2006). It was revealed in an FGD with TOP Support members how even close family members distance themselves from the women since they are afraid to be infected.

My own cousin is even worse, if I walk in front of her, she closes her nose, as if I'm a virus, and my own sister, my own sister, she walks like this...turns around, to avoid me. There's a virus, so she has to turn around. I'm mad at her, I really want to punch the people. I even had fights. That's my own cousin!
(Wanda, 27 years, widow)

Indeed, the discrimination comes from the family first. The neighbours aren't that bad. The family is stronger. At first, I was crying when my sister-in-law did that, it's not a nice feeling. But later on I can accept it. I don't want to care. I let it be, because I get this disease, I have to be more careful. A

consequence is when she visits our home. She's very careful with food. She brings plates from home, to our home. I must tell her like this, 'There's only one thing you can't bring here, the gas cooker'. I tell her that. So, she brings all the utensils, from spoon to Tupperware. She even washes them separately; also she places them separately for her child and for mine... But sometimes I do it too after washing the dishes. But it's not really a problem. I don't care. If I have to think about a small thing, I'll get sicker. It's miserable to have this kind of disease, I'll get more hurt. Later on, when they come home, I try to understand more, I tell them this is mine, this is hers, etc. I just explain it; it's not really a problem. But until now, my sister-in-law still acts the same. Later on, my sister-in-law tries not to hurt my feeling. At first, it was not nice when she started separating things. (Vina, 29 years, widow)

Being unwanted women, seropositive mothers are also vulnerable to being neglected and abused. One of the members, Sinta, had to accept it when her husband beat her up because she thought she did not have another choice and did not dare to save herself. Luckily, Sinta decided to move out and live separately from her first husband when she received some income from YPI. Yet, although they no longer lived together, she did not dare to divorce him, and he continued to bother her and take money from her for his drugs. After the death of her first husband, Sinta married a PLWHA whom she met in a support group meeting.

Dina's case is also interesting. Her husband wanted to have a divorce when he knew her HIV status. He did not want to have the test himself but blamed Dina as she used to be an IDU, and accused her of carrying the virus and transmitting it to their children.

Oh, after knowing the status, he moved out right away. He just left me like that, my body hurt, I was hurt, my world collapsed. A divorce because of HIV. (Dina, 23 years, remarried, passed away in 2010)

Seropositive mothers experience discrimination, not only in the neighbourhood or family, but also in society and from medical staff. A study from 2005 in Jakarta and Bali found that in practice, healthcare staff discriminated against PLWHA and did not adhere strictly to rules or regulations on non-discrimination. Forms of discrimination included refusal to treat HIV positive persons, providing differential treatment, disclosing their status to others, and physical isolation (Merati, Supriyadi, & Yuliana, 2005). In the experiences of TOP Support members, the women were usually suggested not to have children once their HIV status became known, although this is against the written rules of the PMTCT guidelines.

It was suggested if my CD4 level is under 200, I shouldn't get pregnant. But I just took the risk, I wanted to prove to my friends, to a lot of people, that PLWHA can have a child. We only heard from other friends in Jakarta, 'Oh, her child's negative', but we haven't experienced it ourselves. If we see the proof from the pregnancy and birth, we'll have more courage! (Dina, 23 years, remarried, passed away in 2010)

In addition, for those women who get a caesarean section, they soon find out that it is often followed by a sterilization/tubectomy. Viona, Winta, and Maria were all sterilized after having a caesarean section. Their husbands were asked to sign the agreement letter for the sterilization procedure just moments before the caesarean without any chance to refuse it. It was therefore done without the consent of the women. Furthermore, the doctors said they would refuse to give the Caesarean if parents, especially the father, refused to sign a sterilization agreement. Viona was warned not to have anymore children by the doctor who performed the caesarean section of her second child. However, when she gave birth to her third child, the doctor would only do the caesarean after he got the agreement letter for a sterilization signed by her husband.

I was advised not to have children by doctor Evi (who treated her second child): 'You shouldn't have more children', she said. After giving birth she said if you want to have another one, better not right away. If you want to have another one, you should join PMTCT, you must! So, before giving a caesarean delivery to Joshua (her third child), Doctor Bowo told me, 'Is there any agreement letter for a sterilization yet?/Yes, my husband has signed it'. When I met him at Bunda (maternity ward), he told me to have a sterilization, that's why he asked, 'Is there any (letter) for c-section and sterilization?/Yes, doctor'/It is a must'. So I said yes; I was sterilized after Joshua's birth. (Viona, 27 years, widow)

There's an operation right away. I was sterilized, by Doctor Evi. A direct operation, the letter for the operation was made, given to my husband. He agreed, I could not refuse it; I had no choice. This husband (he is her fourth husband) has not had any child (Maria, apprx 40 yeras, remarried)

It would seem that there are efforts being made to prevent children being born from seropositive mothers. This may relate to the government's efforts to control population growth through the Family Planning Program. It may also relate to the perceived cost burden to the government of babies who are born infected, or who are just feared will be infected, with HIV. The medical interventions to prevent

transmission from mother to child, such as sperm washing, insemination, etc., are also expensive. It is intriguing that the women in these cases above defencelessly accepted a sterilization procedure, although it is understandable remembering that they are in a difficult position. A sterilization is done right after the caesarean section and the agreement is mostly signed just before by the husband, not by the woman. In this way, the reproductive rights of the woman are ignored, and the husband, who is regarded as the head of the family, can decide what is best. Additionally, because they receive help to pay for the caesarean section, they have very little bargaining power. As written in the PMTCT guidelines, a caesarean delivery for seropositive pregnant women is actually a must to prevent the transmission through delivery. It may bring a problem for those who cannot afford to do the costly caesarian section. However, the doctors may threaten to refuse to treat the woman if she does not want to go for a caesarean followed by sterilization. In most cases, the women agree to get themselves sterilized. Considering that the relationship between patients and health providers is usually not equal and is dominated by the health providers, such as surgeons and nurses, it is understandable that even TOP Support members cannot avoid the pressure for a caesarean section followed by sterilization.

Lina was the only woman who refused to get the caesarean service from YPI. However, she did it secretly because she would have lost other services. In order to avoid a caesarean section, Lina took a risk and used a traditional method whose safety is questionable. Her first child had been HIV positive and died at the age of three. Later on, Lina married another PLWHA and they had two daughters. According to Lina's mother, Lina took some traditional medicines in order to deliver her babies prematurely. Her second child was born at seven months and her third child at six months. Both of them were born without a caesarean. Lina confessed to her mother that she had intentionally delivered the babies before the due date because if her pregnancies had reached nine months, she would have been registered to have a caesarean without her consent. Lina did not want this because she was scared of an operation, and furthermore, if she had refused it, she would have lost the other benefits from YPI, such as ARV medicines and free formula milk. Lina passed away in May 2009 and never told me the story personally.

6.E. Response to HIV/AIDS

It is fascinating to reveal that based on my observations and analysis of FGD data, the HIV positive women with whom I spoke showed differences in their ways of interpreting HIV. Those who had never had any severe sickness and who typically had little knowledge about the disease identified HIV as a curse caused by their actions, which were considered to go against social norms, i.e. to be passive and

sexually inactive before marriage. They blamed themselves and thought that HIV was a punishment and a sign that now they should live better lives according to the norms of women. In an FGD, most of the seropositive women said that they believed there was a very powerful energy reminding them of their so-called 'misbehaviours' as Indonesian women. Most of these women got married without consent from their parent(s). In this case, they mean their male parent (father) or any male representative of their (extended) family. A marriage without parental consent is considered illegal and a sin. As a result, sexual activities in an illegal marriage are also forbidden. Maintaining virginity is an obligation and a very important matter in a girl's life (Niehof, *Madurese Women as Brides and Wives*, 1987, p. 174; Sidharta, 1987, p. 64), and a girl should be a virgin and sexually inexperienced before a legal marriage (Kroeger, 2000, p. 176). Being pregnant out of marriage is a big sin that cannot be tolerated. For this reason, it is understandable that they feel they have committed a serious sin in their life.

By having HIV, they say they now realize what they have done and that they must do better in order to get back on the 'right path'. HIV is considered as an illness to forgive their sins after having done actions which were against their norms and religion, such as consuming drugs or having unprotected sex.

Firstly, I was pregnant, seven months pregnant. Secondly, my husband was sick.... The illness comes not because we asked for it, it comes from God. We should learn from it. (Winta, 18 years, remarried)

I feel guilty towards my parents; it's karma because I didn't listen to them. My parents were on my side actually, my husband's a junky. I didn't use to steal, but later on I stole for him. My parents advised me. Just like normal parents, they were angry with me and said they wished no happiness for me. It happened what they said. Their curse became a reality. My parents cursed me. They said I'd never be happy, if I'd have a child my child would be sick, that's true! This is what I experience now. What parents say is magic. If I can I want to kiss their feet²⁴. I didn't realize what I did was wrong. Having a disease now I can learn something. God gives us temptations, for each one of us. We shouldn't be naïve. If we're dating junkies, they always think of sex. You don't realize you're doing adultery. God gives me punishment because I've been adulterous. He gives me the disease. God may have said that from above. We don't have to be a hypocrite as a PLWHA, people who date PLWHA must have sex. I'm not a hypocrite, I feel it. I've done a sin. Allah knows the

24 In Javanese tradition, kissing parents' feet symbolizes respect when asking for forgiveness.

sins. I get a warning, the HIV. The sin is that I've had sex before marriage. My parents are angry; we don't realize we've hurt their feelings by rebelling and not listening maybe. There's something to learn, I think so. We get closer to God. Usually we forget the prayers, but not now. I pray more often. (Vina, 29 years, widow)

Yes, it's true. It is the curse, I mean, it is not for me or you, but to your husband and mine. They've done a sin. We were cursed. It's a curse from God... you know. I'm a victim. Back to God, He gives everything to us, He must help too. As a victim, it doesn't mean that I'll get the disease forever. I believe one day, I keep praying and taking medicine regularly, I may suddenly not be sick anymore, I believe that. I believe it will be gone. (Asti, 30 years, remarried)

Sometimes HIV's not a curse, I emphasize it, HIV is not a curse. But sometimes we feel that way. If we don't listen to our parents, we'll get punishment. I've done a sin when I was still a virgin. With this warning, I'm better, I ask for forgiveness. (Sinta, 26 years, remarried)

Every action has a consequence. Not from God, actually. From ourselves, but we don't realize it. Only God allows it to happen so that we can realize it. As a human, we don't realize what we're doing, we think we're right. But, it's not always right. People make mistakes, even though it's a simple sin, or big sin; for God it's a sin. God allows it to happen. But everything's God's will. I didn't use to give donations, now I do. Death is in God's hands, but at least we're ready, we're ready. Especially after knowing my status, I have to be closer to God, I really have to be closer to God because this illness is strange, it is strange in my opinion. What's strange is the ones who have high risks and are not infected, and that those who are not at risk at all, who never have any idea about it, are infected. And then we see, mothers who are in a very bad condition, but the children are not infected. On the other hand, the mothers seem healthy, yet the children may be infected since their birth. If we think logically, it's difficult to understand, maybe it's like this, maybe it's like that. It all comes back to Allah. I wear a veil (the Moslem hijab), just lately... It's been a year after giving birth to my child. Especially after knowing my status, I have to get closer to God, I really have to get closer to God since this illness is strange in my opinion. When I knew it for the first time I had mixed feelings, all the feelings became one. Have you ever imagined if a durian (large thorny-skinned fruit) falls on your head? I think that's what I felt... (Wiwid, 29 years, married)

Those who had experienced severe illness due to HIV/AIDS exhibited a better understanding of the fact that they got infected because of their so-called risky behaviour, not because of a curse or punishment from God. Nevertheless, their behaviour was still considered a sin and HIV the punishment for having committed the sin. Lina and Wanda replied cynically at the FGD when they were asked to comment on their peers' answers.

That's a sin of both of us, husband and wife. We dated and made love a lot. (Lina, 22 years, remarried, passed away in May 2009)

Only *Malin Kundang* was cursed²⁵. It's not a curse, it's a disease. Actually, it's a blessing that I get HIV. *Alhamdulillah*. Because I do remember God now. I realize it now, I ask for forgiveness. I used to pray once a day, now all of them (all five times, Moslems pray five times a day). At least we've got something to be taken to another world (when we die). (Wanda, 27 years, widow)

It appeared that the HIV positive women felt particularly guilty when their children had to pay for their so-called sins, as described by Wiwid and Vina below.

It's not a burden for me, what bothers me is that my child is also infected. I feel guilty. If (my health) gets worse, but my child is healthy, I can accept it. Allah decides your fortune. I don't know how but there must be a way. What I'm concerned (about), what makes it worse, is when I die and my child is also sick. That's my concern. Who will take care of him? (Wiwid, 29 years, married)

When I knew that she's positive (her only daughter) I was very sad, I feel like I've done the sin. I try to pay for it. I give her medicines regularly, I give her healthy food. If I can make her happy from my own income, I try to buy anything she wants. That's what I do. (Vina, 29 years, widow)

Many of the women do not regard HIV/AIDS as a disease but rather as a punishment for their sins, given by God in accordance with the prevailing religious norms. Religion not only provides them with an answer to the question 'why me?' but also provides them with a way to deal with the curse, i.e. they can cleanse themselves and wear a veil.

25 Wanda is referring to a famous Indonesian fable in which *Malin Kundang*, the son, is cursed by his mother.

Because these women did not feel that they had HIV, they did not feel the importance of taking ARVs and visiting the doctor regularly. Discontinuance and non-compliance was not an unusual thing among them. For Dina, Winta, and Lina, although they received ARVs free of charge, they still did not attend the clinic regularly to get the medicine. I think this was because they did not feel ill. For most people, doctors and medicine are related to the condition of being ill. One does not go to see the doctor or take medicine if one does not feel like one is sick. Asymptomatic people may refuse medical treatment even though physical abnormalities of the body are found (Helman, 2001, p. 104). This happens also among TOP Support members; even if they feel some symptoms they do not regard them as symptoms of HIV but of the opportunistic infections or of the medications themselves. When they have an opportunistic infection, the doctors will suggest that they buy medicine to treat it; medicine which is, however, relatively expensive. Then, usually for economic reasons, they become demotivated even to get the free ARVs from the referral hospital or to attend health check-ups.

The side effects of ARVs were stated as another reason why they do not take them regularly. The side effects are even considered to be more of a disease than the HIV itself. Tiara refused to start ART even though her CD4 count was very low (at 97), as she was afraid that the side effects would have a negative impact on her appearance, such as producing dull skin, a fatty body, or a pimpled face.

Asti shared with me her experiences of taking ARVs. Before ART, Asti had been on TBC treatment for tuberculosis. Both medications, the TBC treatment and the ART, caused serious side effects for her body. She later tried a different type of ARV, but it did not help. Eventually she has found an ARV type which has the least side effects.

I got TBC, very bad, very ill, seriously ill. I took some medicine, but the medicine had 'burned' me, made me weak, and (I was) totally ill. As if I was literally burned, I was black as if I would die anytime soon, it's so scary to have a look at myself, I swear...! I was given the medicine for a week, and then I stopped and had a consultation with *Puskesmas*. Then I was given the same medicine by the doctor. The medicine costs 200,000 (IDR). Later I was tested at Dharmais (hospital). That's right, I got ARVs. I quit taking ARVs because of nausea, itchiness. I took Duvinevin, now I take Duviral Evaviren. Evaviren sometimes makes me dizzy and I hallucinate, about half an hour to an hour. (Asti, 30 years, remarried)

Titi and Wanda place no importance on consulting their doctor with their complaints. Whenever they pick up their ARVs at the referral hospital, they also have an obligation to consult the doctors about their health problems, in order to

detect opportunistic infections as early as possible. However, medication for the opportunistic infections is costly. Titi and Wanda shared their stories below.

If, for example I've got complaints...such as my liver hurts or this hurts that hurts, Prof. will give me extra medicine. This extra medicine costs already around 400 (400,000 IDR), only if I'm very ill will I be given. The capsule which costs fifty thousand each, a capsule, and I have to take 150mg, three capsules. But sometimes I am reluctant to tell the Prof... hmm... if I have a certain complaint. I'm afraid of the medicine (because it's expensive). So, before seeing him I will do 'it' myself first (self-medication). Such as taking much juice, you know, taking juice or buying vitamins myself. If I get better, I won't see the Prof. But if I can't help it, if I've done everything, I have to see the Prof. (Titi, 24 years, married)

I never talk to the doctor about that because if I do I must get medicine from him. He must give medicine if we have complaints, I don't feel like taking it. I don't tell anything. The doctor only asks me if I have complaints or not. If he asks and I don't have any complaint, he gives only the prescription of Nuviral Deviral. (Wanda, 27 years, Widow)

6.F. Discussion

Glick (1998) argues that there are three dimensions of a diagnosis statement: (1) evidence, the empirical indication which can be proved by signs and symptoms; (2) the process, which describes what actually happens to produce the evidence; and (3) the cause or agents, who/which in some ways bring their powers to bear against their victims. I have noticed that in the TOP Support group, most members never feel that their symptoms are evidence of HIV. In fact, anybody who has HIV will eventually develop AIDS, at which time symptoms of opportunistic infections will appear. However, being HIV positive does not always mean that an illness exists or that there is any change in one's health condition. Many of the support group members did see evidence in the fact that their children and husbands have died, but they did not experience the symptoms themselves.

The distinction between a disease and an illness refers to the different symbolic perception and explanation between doctors and patients about the sickness (van der Geest, 1987, p. 31). A disease is a clinical fact, and refers to something related to an organ which is based on scientific rationality and the objective observations of doctors. A symptom of the disease can only have meaning when it is explained by objective and physical changes. In contrast, an illness refers to the subjective

response of an individual and the people around him regarding his ill health, which includes his experiences and the meaning he gives to these experiences (Helman, 2001, pp. 79-84). Semiotically, an individual will interpret his illness based on the symptoms he experiences. Cultural background and personal experience have an influence on a person's thoughts about certain symptoms, which eventually help decide upon the meaning of the illness to that person (Frake, 1998; Glick, 1998; Good, 1998).

It is possible that someone who has HIV has not had any related health complaints, since they have not yet reached the stage of AIDS. Thus, even if a person has experienced some physical symptoms, if these symptoms are not severe they might not consider themselves to have a health problem (Kaplan, Sallis Jr, & Patterson, 1993, p. 278). Without symptoms, one cannot actually diagnose one's illness (Frake, 1998; Glick, 1998; Good, 1998). This is the reason why it is hard for TOP Support to emphasize to the seropositive women that HIV is a disease. For most TOP Support members, having HIV is rather the consequence of having committed a sin that goes against their bio-social identity as a woman and as a mother.

It is interesting to know that without symptoms which function as evidence of HIV, the HIV positive women in TOP Support can explain the process and cause of the disease. The 'agent' which caused the disease was the woman herself (perhaps because she was an IDU) together with her (IDU) partner, and what really happened was the sin of losing her virginity as a result of improper sexual relations. Interestingly, the women blame the risky behaviour of their partners, instead of their own behaviour, as the cause of HIV, even though some of them were still sexually active with multiple partners and/or active IDUs. It is a defence mechanism of the seropositive women to define themselves as innocent and devoted women, even though they were aware of their own risky behaviour. Emphasis on men's sexual permissiveness enables the women to take on an innocent and devoted motherly role as a mechanism to rid themselves of the stigma of HIV.

Their bio-social identity as mothers also means that they display more concern about the health of their husbands and children than for their own. Because the ART causes some side effects, they think that the symptoms of the disease can be cured by not taking ARVs. In addition, though many of them receive ARVs for free, to collect the medication requires money for transportation; money which they feel they need more to feed their family. Their ignorance regarding taking ARVs regularly and treating opportunistic infections are evidence that they do not consider HIV as a worrying disease.

In my opinion, their response has also been influenced by their (socialized) feminine characteristics. They have a passive response to the stigma and discrimination against them, and avoid conflict or discriminatory treatment. For example, if there is a family member who discriminates against them, they might

choose to avoid contact with the family. Another example is when the women face a caesarean section followed by a mandatory sterilization; they either accept the decision made for them or secretly engage in other risky practices, which actually put them and their babies in danger. The case of Lina, who twice took traditional medicines to prematurely induce labour in order to avoid a caesarean section, provides a vivid example of this.

Even though they face a dilemma because they know that their children have to pay for their sins by having HIV at birth, the women are still very eager to create a family and have children as they have to keep up their motherly role. In Indonesia, a woman's identity is always related to fertility, and giving birth and producing offspring are compulsory in order to give a woman stronger status in the community (Bergink, 1987; Bringgreve, 1987; Jordaan, 1987; Sidharta, 1987). According to Ulanowsky and Almond (1996, p. 38), seropositive women may decide to remain childless, but "knowing that her prognosis is bad, or even anticipating a short life expectancy may provide a very strong reason for a woman to seek fulfilment in motherhood". Furthermore, a sense of insecurity and a lack of social security mean that the women may try to have as many children as possible, as this will guarantee them a comfortable retirement in their old age. PMTCT provides the promise of giving birth to HIV negative children as social insurance; and since the women do not have symptoms they do not see any good reasons for not having a child.

A marriage also brings an advantage for them economically. Women are socially defined as housewives who are dependent on their husbands' income, regardless of their actual contribution to their families (Suryakusuma, 1996, pp. 101-102). Being a secondary earner, a woman is never considered by others (nor herself) as a breadwinner. The TOP Support members also reflect on this idea. They do not have any confidence that they could earn money to take care of their children alone, and they very much depend on the (extended) family to take care of them and their children. Instead of having a secure job, which most of them cannot get because they do not have good educational backgrounds, they prefer to seek a partner who can financially support them and their children. TOP Support becomes a place where they can meet their future partner.

In the next chapter, I will explain how the women pragmatically use their HIV positive status to access individual benefits.

Table 1:
TOP SUPPORT MEMBER LIST²⁶

| No | NAME | MARITAL /SEXUAL RELATIONSHIP (PAST/PRESENT) | HIV TRAJECTORY | TREATMENT TRAJECTORY |
|----|---|---|---|--|
| 1 | Vina 29 Widow Senior high school, graduated with secretariat vocational training Moslem | She is now in a relationship with an HIV positive man and sexually active | She was referred by the hospital that was taking care of her severely sick daughter. She believes that her husband infected her and their only daughter. Her IDU husband died in 2003. He knew his positive status but refused to take ARVs until he died. Her daughter tested positive at the age of 3 months in March 2002 and has been on ART since. | She started ART in October 2002. Because of the side effects from Lamifudin, in 2005 she started line 2 ARVs with Kaletra. She routinely checks her CD4 count and viral load. In 2006, her CD4 count was 172. She has never experienced any severe opportunistic infections. |
| | Yuna 32 Widow Senior high school, graduate Moslem | She is now in a relationship with a man and is sexually active. She has 2 uninfected boys. | She tested positive after her HIV positive IDU husband died in 2004 from severe typhus. | She has been on medication (Zidovudine, Nevirapine, Lamifudin) since April 2004 as her CD4 count was 169 and she was 8 months pregnant. As she got anaemia, she changed Zidovudine to Stavudine. She has never experienced any severe opportunistic infections since she tested positive. |

²⁶ The condition of the informants are continuously being update through unconditionally meetings, emails, telephones, or test messagings since the field research was conducted in 2006 up to 2010

| | | | |
|--|---|---|--|
| <p>Willy 25 Separated Senior high school, graduate Catholic</p> | <p>She lives separately from her husband who has recently remarried to another woman.</p> | <p>She got tested after her husband tested positive, but both of them have been IDUs.</p> <p>She recently stopped taking the drugs as her best friend passed away from an overdose.</p> <p>Her husband is still actively using drugs.</p> | <p>She has been on ARV medication since 2006 as her CD4 count dropped, but has never experienced severe opportunistic infections.</p> <p>Her husband stopped ART. He was in jail and never shows up anymore.</p> |
| <p>Dini Married Passed away in 2007 Education, age and religion: no record</p> | <p>She was married to an IDU.</p> | <p>She took VCT after her husband was severely sick. Both of them have now passed away.</p> <p>They had two uninfected children.</p> | <p>Before she died, she was on ARV medication as her CD4 count had been low since 2006, a year before she passed away in 2007</p> |
| <p>Lina Passed away at the age of 25 in 2009 Remarried to a PLWHA Junior high school, graduate</p> | <p>She was married to her first husband, who died of AIDS in 2005.</p> <p>She had 1 son with her first husband, who died of AIDS at the age of 3 years in 2007. Her son had never been medicated.</p> <p>She was sexually active with some boyfriends before she remarried to another PLWHA.</p> <p>She had 2 uninfected daughters from her 2nd husband. Both girls were born prematurely.</p> | <p>She found out her status after her baby boy was severely ill. She thought that she was infected by her first husband.</p> | <p>She was on ARV medication since March 2006 and died of Tuberculosis</p> <p>She stopped ART several times, even though she got it for free at the referral hospital.</p> |

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| <p>Winta 18 Remarried Junior high school, graduate</p> | <p>She used to work as a call girl and married her boyfriend after she got pregnant at the age of 15. Her first husband was died of AIDS in 2004.</p> <p>She was sexually active before she remarried. Her new husband has never been tested and was recently in jail.</p> <p>She has had 2 children (one from each husband). Her first child is HIV positive, and the second one was uninfected but died in 2009 after a fall from her bed that caused a severe head injury.</p> | <p>She found out her status after her husband was very ill.</p> <p>She believes that she was infected by her first husband who is an IDU.</p> | <p>She has been on ARV medication since 2005 but has never experienced opportunistic infections.</p> |
| <p>Wanda 27 Widow Senior high school, graduate with illegal diploma Moslem</p> | <p>She was an active IDU and is still using oral drugs.</p> <p>She was sexually active and got pregnant by another man (who later became her first husband) while her IDU boyfriend was at rehabilitation. She remarried to her boyfriend after her first child was born.</p> <p>She has had some sexual relationships after her second husband died.</p> <p>She has 2 children, one from her first husband and one from her second husband, neither of whom have HIV.</p> | <p>She had VCT after she was very ill.</p> | <p>She started the ARV medication in 2005.</p> |

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| <p>Wiwid 29</p> <p>Married</p> <p>Senior high school, graduate</p> <p>Moslem</p> | <p>She is married to an IDU.</p> | <p>She did not know that her husband was an active IDU before her only baby boy was very ill and died at the age of 3 month in 2006.</p> | <p>She started medication in 2008 when she felt a problem with her stomach, but she has never experienced any severe opportunistic infections.</p> |
| <p>Sinta 26</p> <p>Remarried to a PLWHA</p> <p>Senior high school, graduate</p> | <p>Her first husband was an IDU and had several extra marital sexual relationships with women.</p> <p>She is now married to another PLWHA after her 1st husband died of AIDS.</p> <p>She has 2 uninfected daughters from her 1st husband and plans to have another child with her 2nd husband.</p> | <p>She did not know that her first husband was an active IDU.</p> <p>She got tested when her husband was very ill.</p> | <p>She has been on ARV medication since 2004 due to low CD4 count.</p> |
| <p>Asti</p> <p>Remarried to a PLWHA</p> <p>Senior high school, graduate</p> <p>Moslem</p> | <p>She was an active IDU and was married to an IDU.</p> <p>She has 2 uninfected children from her first husband.</p> | <p>She tested HIV positive after her husband was very ill.</p> <p>She always said that she had been infected by her husband, but she is also suspicious as she was also an IDU before marriage.</p> | <p>She has been on ARV medication due to low CD4 count.</p> |

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| | <p>Tiara 22 Widow Bachelor diploma degree, graduated Moslem</p> | <p>After her IDU husband passed away, she has had some relationships with other men, some of whom were also PLWHA. She has 1 son from her husband who is also HIV positive.</p> | <p>She believes that she was infected by her husband as she has never been an IDU and never had sex before marriage.</p> | <p>She refuses to take ARVs although her CD4 count is already very low (97 in 2009). She is afraid of the side effects. Her son started medication in 2008.</p> |
| | <p>Netty 23 Married Senior high school, graduate</p> | <p>She is married to an IDU. She has one uninfected child who is healthy.</p> | <p>She found out her positive status when she went for a pregnancy check up.</p> | <p>She is not on medication, as her CD4 count is still higher than 300.</p> |
| | <p>Dina Passed away in 2010 at the age of 25 year Remarried Senior high school, graduate Moslem</p> | <p>She was divorced from her husband who had never been tested with whom she had 3 children. She was remarried to an IDU with whom she has 1 child.</p> | <p>She found out her status after her 3rd child and she herself was severely ill. Her 4th child from the 2nd husband is uninfected</p> | <p>She has been on ARV medication since 2004 .</p> |

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| <p>Ika 32</p> <p>Senior high school, graduate</p> <p>Moslem</p> | <p>She is divorced from her first husband, with whom she had a child.</p> <p>She remarried an HIV positive IDU and has 4 children with him.</p> | <p>She knows her positive status from the mobile VCT when she was pregnant with her fourth child.</p> <p>The first 3 children have not been tested yet. Her last 2 children are uninfected.</p> | <p>She has been on ARV medication since 2009 after giving birth by c-section to her fifth child as her CD4 count was very low.</p> |
| <p>Titi 24</p> <p>Married</p> <p>Diploma III school, graduate</p> <p>Moslem</p> | <p>She is married to an IDU, with whom she has a son who is HIV negative.</p> | <p>Her husband knew that he was positive after donating his blood. She got VCT when she was pregnant.</p> | <p>She has been on medication after her CD4 count was very low since 2006, but has never experienced severe opportunistic infections.</p> |
| <p>Irene 23</p> <p>Married</p> <p>Senior high school, graduate</p> <p>Religion: no record</p> | <p>Her first husband was an IDU, with whom she had an uninfected child.</p> <p>She is remarried to an uninfected man with whom she has an HIV positive child.</p> | <p>She got tested when her second child from her second husband was severely ill. Her child passed away in 2008.</p> | <p>She started ARV medication when her CD4 count was 28 in 2006.</p> <p>At our last contact she was very ill.</p> |
| <p>Ade 22</p> <p>Married</p> <p>Junior high school, graduate</p> <p>Religion: no record</p> | <p>She is an IDU and married to an uninfected man with whom she has a child.</p> | <p>She knew her status when her only child was very ill. Her child then passed away of AIDS.</p> | <p>She is on ARV medication and at our last contact was suffering from toxo-plasma.</p> |

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| <p>Evi 23</p> <p>Widow</p> <p>Senior high school, graduate</p> <p>Religion: no record</p> | <p>Her husband passed away before knowing his status.</p> | <p>She has known her status after having an obligatory medical check-up from her work place, a Japanese restaurant.</p> | <p>She is on medication due to low CD4 count.</p> |
| <p>Viona 27</p> <p>Widow</p> <p>Diploma I school, graduate</p> <p>Christian</p> | <p>She was married to an IDU, with whom she had three children.</p> | <p>She and her husband were tested when their 1st child was very ill. They were all positive.</p> <p>She has another 2 children who were born after she joined the PMTCT program. Both are HIV negative and healthy.</p> <p>Her husband died after she gave birth to her 3rd child.</p> | <p>She and her 1st son are on ARV medication, but she has never experienced severe opportunistic infections.</p> |
| <p>Atik 29</p> <p>Divorced</p> <p>Diploma III school, graduate</p> | <p>She is recently divorced from her IDU husband with whom she has 2 children</p> | <p>She did not know that her husband was an IDU until he was very ill. After that, she took VCT.</p> <p>Her first child died before being tested, her second child is HIV positive.</p> | <p>She is on ARV medication.</p> |
| <p>Siti 26</p> <p>Married</p> <p>Senior high school, graduate</p> <p>Moslem</p> | <p>She is married and has one child with her husband.</p> <p>She does not know her husband's status.</p> | <p>She got tested after her child was very ill.</p> | <p>She has been on ARV medication after her CD4 count was very low since 2009.</p> |

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| <p>Ruminta 36</p> <p>Remarried</p> <p>Senior high school, graduate</p> <p>Christian</p> <p>Passed away in 2008</p> | <p>She was married to an IDU with whom she had an HIV positive child.</p> <p>She remarried and had a second child who was uninfected.</p> | <p>She tested positive after her first husband died.</p> | <p>She was on ARV medication before she passed away in 2008.</p> |
| <p>Maria</p> <p>Remarried</p> <p>Moslem</p> <p>Age and Education: no record</p> | <p>She has been married 4 times and has children from each husband.</p> <p>In total she has 5 children, though one of them died in a car accident.</p> <p>She used to work as a prostitute.</p> | <p>She knew her HIV status from the mobile VCT. She is unsure which husband infected her.</p> <p>All of her children are uninfected.</p> | <p>Her CD4 count is still 700, and she has never experienced any severe opportunistic infections.</p> |
| <p>Dessy</p> <p>Age: no record</p> <p>Married</p> <p>Senior high school, graduate</p> <p>Moslem</p> | <p>She lives separately from her uninfected husband as she has been in prison several times.</p> <p>She has 2 children with him.</p> | <p>She was an active IDU and often relapses.</p> <p>She got tested after her first child was very ill. Her first child was positive; her second baby has not been tested yet.</p> | <p>She has been on medication due to low CD4 count since 2004.</p> |