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

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Chapter I

Introduction

It was a blistering April afternoon in Karawang when I first met Nani at the Yayasan Pelita Ilmu (Light of Science Foundation – hereafter YPI) village post in 2005. The small-framed woman seemed quiet and shy. She, along with three others, had come to participate in a focus group discussion for HIV-positive women. Nani, a divorcee, was from Cianjur, a region in the southwest of Karawang district. She had come to Karawang after a YPI volunteer, whom she met in Bandung (the capital city of West Java province), had asked her to join YPI. After one year of working as a volunteer, she was recruited by another NGO as an outreach worker for their HIV/AIDS prevention program. In the focus group, Nani and two other women revealed their desire to have children. But they worried about the risks of transmitting HIV to the child.

When I started this study, Nani had just remarried – with Rusdi, a bus driver from the next district. Having undergone ARV therapy since 2005, Nani was looking forward to the future. Her desire to become a mother was so strong that she had decided to remarry. Her first pregnancy miscarried, but a few months later she was pregnant again. She carried the second pregnancy to term until she underwent a caesarian section as part of the prevention of mother-to-child transmission (PMTCT) program at the national hospital. Nani gave birth to a baby boy in February 2008. When I visited her in her rented room, she was delighted. She said her dream had come true.

Six months later, after she finished her contract in Karawang, she returned to her village. I sometimes sent her an SMS to know what she was up to. Nani was happy because her son was growing up. He was healthy and had tested HIV-negative. Then, in early November 2010, I received an unexpected SMS from her husband informing me that Nani had been severely ill for the past three months. He told me that she had stopped ARV treatment since experiencing difficulties obtaining medicines on time at Karawang district hospital. She was upset and desperate in the face of
uncertainty. In the middle of November 2010, Nani passed away, leaving her beloved child to her younger brother.

In September 2005, I met Olivia, a nine year old girl from Cilamaya sub-district. She had come to the YPI village post with her grandmother. Olivia’s mother, who was HIV-positive, had died not long after giving birth to her. Olivia was the first case of PMTCT in Indonesia, when free ARV treatment was not yet available. She was born through C-section, handled by doctors from YPI. She is HIV-negative.

My initial acquaintance with Nani and my meeting with Olivia raised many questions: How does being HIV-positive influence one’s desire to have children? Will the spouse/partner consent to conceive a child by risking infection (for HIV discordant couples) and the baby being infected at birth? If the partner refuses to conceive, does he/she breach the reproductive rights of his/her partner? Whether or not the couple wants to have a child, how do they meet their sexual desires? What are their sexual and reproductive practices? How do they negotiate to avoid the risk of infection? These questions made me realize there have been many blind spots in previous studies of HIV and AIDS in Indonesia. As far as I know, most HIV/AIDS-related research has focused on high risk groups and behavior, the cultural construction of HIV/AIDS, and program interventions, while overlooking people living with HIV/AIDS (PLWHA) or Odha (Orang dengan HIV/AIDS). Specifically, the sexual and reproductive desires of PLWHA have gone unstudied. But my research shows that young HIV positive men and women in Karawang are struggling to continue their lives, including their family lives. They want a reproductive future.

Further questions came to mind. Why did Nani have to die? Could it have been prevented? How does the state address the needs of PLWHA? To what extent do the poverty and stigma surrounding PLWHA hinder their access to health services? How do people live with HIV? Why do they die when treatment is available? These questions place this study in the wider socio-cultural context of Karawang society.

In any society, we need to consider the role of gender and sexuality in determining vulnerability, particularly in the realm of sexual and reproductive health. Men’s concerns are often neglected despite their influence over couples’ reproductive decision-making (Hardon 1995:122). In Indonesia, the reproduction and sexuality of
HIV-positive people is ignored; the reigning assumption is that once people are infected with HIV, they no longer have sexual intercourse and/or should not have children. The idea of parenthood fades away. As Paiva states, “HIV infection does not fit the meaning of wife-mother or husband-father…. At the same time, those who are HIV-positive are rarely thought of as fathers, mothers and spouses” (Paiva et al. 2003:98).

For HIV-positive young people, the situation is even more problematic. Young people are often regarded as asexual, though the reality is clearly different. A survey in Jakarta showed that 53% of male injecting drug users (mostly between the ages of 16 and 25) have had sexual intercourse with more than one partner, while 20% have had sex with sex workers. Most do not use condoms (Family Health International 2005). This not only puts their sexual partners at risk of HIV; it risks unwanted pregnancy. The sexual and reproductive needs of HIV-positive young people thus need to be addressed to reduce the risks of transmission to their partners, which in turn will reduce transmission from mothers to children. Nevertheless, changing sexual practices remains difficult as it intertwines with gender, class, religion, and other cultural factors (Adrina et al. 1998; Dumatubun 2003; Lake 1999; Sumiarni, Wardhana, and Abrar 1999).

The rapid increase in the number of HIV-positive people in Indonesia – particularly among male injecting drug users – has increased rates of vertical transmission, necessitating a PMTCT program in the country. Indonesia’s relatively new PMTCT program is integrated into existing health services, particularly maternal and child health and family planning. Yet, such clinics are typically not designed to cater to men, let alone young people. As HIV/AIDS-related information and services are primarily provided through family planning and maternal and child health clinics, men and young people are less likely to be informed about HIV/AIDS prevention, care, and support as well as options for treatment.
Fertility, marriage, gender, and sexuality: the Indonesian context

While fertility remains highly valued in Indonesian society, the recent decline in fertility rates due to family planning has been dramatic. The estimated total fertility rate declined from 5.6 births per woman in 1968 to 2.6 births per woman in 1996, a drop of over 50%. Indonesia Demographic and Health Survey data from 1997 reveal that women in urban areas have fewer children (2.4) than women in rural areas (3.0). Nationally, the contraceptive prevalence rate increased from 52% in 1994 to 55% in 1997 (Ministry of Health and WHO 2003: 37-38).

Fertility is embedded in marriage. Men and women are expected to marry, and if they do not, negative labels are attached to them. The labels for women are associated with their sexual morality; the labels for men to their sexual potency. As is generally known, to be married is a powerful norm throughout Indonesia. It is reflected in one of the basic principles of Indonesian state ideology, the *azas kekeluargaan*, or ‘family principle’, which holds that the heterosexual family is the fundamental unit of the nation (Boelstorff 1999:491). The imperative to marry is invariably related to the obligation to have children. It is common for Indonesians to ask someone whether they are already married and have children.

For an Indonesian woman, being a mother is considered essential for fulfilling the ideal of womanhood. Having children provides her with a social identity and guarantees her social status within family and kinship groups. Motherhood also has an economic basis for it guarantees women support from their husbands, especially in the event of divorce, though in reality this is not always the case. For men, marriage and fathering children demonstrate masculinity and virility.

For HIV-positive people, particularly women, reproduction is a complicated matter. In case of pregnancy, women can obtain free antiretroviral (ARV) medicines and caesarian deliveries. As HIV-positive pregnant women often learn their serostatus late during antenatal care or after their husband/child has been tested, abortion is hardly an option. In any case, abortion is morally and legally unacceptable in Indonesia, though illegal abortion services — traditional as well as modern — are available. HIV-positive women
thus require information to make informed choices about their reproductive futures, such as the best time to get pregnant (if they want this), antenatal care, caesarian versus normal delivery, abortion, breastfeeding versus formula milk, ARV treatment, and condom use as protection against reinfection. For discordant couples (where one partner is HIV-positive and the other is negative), reproduction means greater risk of infection. Some HIV-positive individuals do not disclose their status to uninfected partners for fear of losing the marriage or relationship (Ford et al. 2004).

How do HIV-positive people deal with such powerful norms of fertility, marriage, and reproduction? How do they decide whether to marry and whether to have children? If an HIV-positive couple wants to have children, how would they go about fulfilling this desire? Do PMTCT services provide them with proper counseling concerning their sexual and reproductive health?

Gender inequality is an important factor in the spread of HIV in many countries. Women are more vulnerable to HIV for biological, economic, political, and socio-cultural reasons. Indonesian women are less educated and have lower incomes than men in the same social circumstances. The disparity is greater among poor families. Poverty and lack of education hamper women’s negotiating power, which extends to control over their bodies and sexual relationships. Women are doubly burdened by HIV/AIDS: if a family member gets infected, they must care for the ill person in addition to earning an income and doing the domestic work.

Power relations between men and women are produced and perpetuated by beliefs and practices about the appropriate behavior and treatment of men and women. In contemporary Indonesia, religion is the primary standard guiding gender roles and expectations. Religion reinforces the position of the husband as the head of the family (and breadwinner) and the wife as housekeeper, set forth in the 1974 Marriage Law promulgating the New Order ideology on manhood and womanhood (Katjasungkana and Wieringa 2003).

Different ethnic groups in Indonesia have their own gender traditions. For instance, among the Minangkabau, a matrilineal society in West Sumatra, property is inherited through the mother’s line. Minangkabau men, however, retain their power since family and community decision-making are in the hands of ninik mamak – the brothers of female property holders. In contrast, the Batak in
Northern Sumatra and the Balinese are patrilineal societies where women are unable to inherit, are economically dependent on men, and are excluded from public decision-making. In Java and Kalimantan, most ethnic groups have bilateral kinship systems that provide greater equality between the sexes; women play prominent roles in commerce and agriculture though they are traditionally excluded from political life. Alongside such differences, some ethnic groups do not clearly differentiate between male and female. The Bugis of South Sulawesi, for example, recognize more than two genders and have a more fluid understanding of sexuality (Blackburn 2004:8). The Ponorogo of East Java accept same sex relationships between warok (older men with magical powers) and young boys (Oetomo 1991).

Colonial regimes, the bureaucratic state, religious institutions, and global capitalism have affected Indonesian notions of gender and sexuality. Hence there may be substantial differences among women and men from different classes, religions, ethnic groups, and geographic regions. Before the reformasi – the reform period that followed the downfall of President Soeharto in May 1998 – the New Order regime’s gender ideology sought to control women through their roles as wives and mothers. Two state-run women’s organizations – Dharma Wanita and, at the community level, Pembinaan Kesejahteraan Keluarga (PKK) – organized and trained women in their roles as caretakers of house and family (Suryakusuma 1991; Wieringa 1998). Women were deemed the gatekeepers of family morality to guarantee the morality and orderliness of society as a whole. Women were supposed to be sexually passive, obedient, and caring towards their husbands as well as devoted mothers. This gender ideology was entrenched in legislation; the role of women was seen as kodrat (destiny) (Katjasungkana and Wieringa 2003).

The reformasi movement challenged this gender ideology, with NGOs, religious groups, women’s organizations, and international organizations demanding greater gender equality. Some political parties and religious groups, however, have espoused views more conservative than the dominant ideology. Islamic-based local regulations to control women in public space have sought to stamp out prostitution and institute curfews and dress codes for Muslim women (Noerdin and Aripurnami 2005). Recent years have witnessed more complex formulations of gender, showing that the
roles and identities of men and women are subject to change under the dynamics of social, economic, political, and cultural forces.

Sexuality is a social domain in Indonesia, with particular attention to the virginity of unmarried women and the fidelity of married women. Nevertheless, recent studies have revealed that more liberal sexual attitudes and behaviors are common among urban youths. For instance, the *pecun* (*perempuan cuma-cuma* or women free of charge) are young urban women – either students or teenagers – who provide boyfriends or clients with sexual services in exchange for gifts or cash. The *pecun* phenomenon fits within this broader sexual discourse, where the dominant view of women as good wives, mothers, and citizens is being challenged by the behavior of educated urban youths (Surtees 2004).

HIV/AIDS in the Indonesian archipelago can be characterized as a relatively invisible epidemic. Given the low official number of cases, it is not surprising that for most people, HIV/AIDS remains a distant reality. A focus group discussion among male community leaders in Rawa Bunga district in Jakarta in September 2005\(^1\) revealed that their knowledge of HIV/AIDS remained superficial. This is not to suggest, however, that people are unaware of the presence of HIV/AIDS, which has been the subject of public awareness campaigns and controversial debate.

Ideas about HIV/AIDS are closely related to ideas about gender, sexuality, and the body. This can be seen in how female sex workers are blamed for HIV/AIDS; the body of the female sex worker has indeed become the locus of the disease (Pisani 2008), pitting premarital and extramarital sex against sexual morality. The Indonesian state has moreover always contended that *ketahanan keluarga* or family resilience – religiosity, monogamy, and harmony – is the best way to avoid moral deficiency and physical disease.

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1. The focus group was part of action research on PMTCT in Jakarta, where I was one of the team members. The project involved the YPI and the University of Amsterdam, supported by Medisch Committee Nederland–Vietnam (MCNV).
Research setting

Karawang district is located on the northern coast of West Java, approximately 70 km from Jakarta. Traditionally, the main source of livelihood has been agriculture and fisheries; in the 1970s and 80s, Karawang was known as the ‘rice granary’ of West Java. Rapid industrialization over the past twenty years has transformed rice fields into industrial zones, attracting more people – particularly rural women – to work in factories. Migration to the big cities, especially Jakarta, is another means for people to improve their living standards. Many rural women have also ventured abroad, particularly to the Middle East where they serve as domestic workers.

Karawang is one of the five lowest ranking districts in West Java on the Human Development Index. The district ranks fourth in terms of cumulative HIV/AIDS cases in West Java. As of 2004, 54 cases of HIV/AIDS had been reported, including Indonesia’s first case of an HIV-positive pregnant mother in 1996.

Prostitution in Karawang can be traced back to the time when, prior to Dutch colonization, Javanese kings practiced concubinage. Koentjoro (1994) states that the areas that endorsed concubinage among the royal Javanese families were Indramayu, Karawang, and Kuningan in West Java; Pati, Jepara, Grobogan, and Wonogiri in Central Java; and Blitar, Malang, Banyuwangi, and Lamongan in East Java (cited in Hull, Sulistyaningsih, and Jones 1997). These areas are still renowned as ‘suppliers’ of sex workers to the big cities.

Although West Java consists of Muslim communities – ethnically they are called the Sundanese – with various levels of religiosity, the people of Karawang are culturally distinct from the rest of West Java. In general, the people of West Java can be divided into three distinct groups: those living in Banten in its western part, those living in the highlands (Priangan), and those living on the north coast (pesisir) (Jones 2001:69-70). The pesisir region includes Cirebon, Indramayu, Subang, and Karawang. In this area, and West Java more generally, age at first marriage for females tends to be lower than in other areas, with the exception of East Java. Jones (1994) states:
In rural West Java, among cohorts born between the early part of the twentieth century and the end of the 1940s, one-quarter of girls were married by their fifteenth birthday, one-half by their sixteenth birthday, and three-quarters by their eighteenth birthday. These patterns were very stable over time.... By the late 1960s and early 1970s, a slight rise in marriage ages was detectable, but it was a very modest rise, adding less than a year to the earlier prevailing age at marriage (cited in Jones 2001:68).

Not surprisingly, divorce was common in these pesisir communities. Divorce could occur at any time, sometimes soon after marriage, and could be followed by another marriage and divorce. Divorce was, and remains, one of the push factors for young widows entering sex work.

Karawang district is also vulnerable due to its accessibility from the north coast highway, the main East to West artery linking the big cities on Java. Large mobile populations of for example truck and bus drivers – the usual customers of sex workers – ply this highway. Sex workers await clients at the many food stalls along the road. Karawang can be considered a high risk area for HIV/AIDS.

The Karawang people are sexually more expressive than the other Sundanese peoples of West Java. Sexuality is openly displayed in their traditional dance performance, the dombret, often performed after harvest time. Erotic movements of the hips, breasts, and buttocks are performed by female dancers who usually wear kebaya (traditional clothing) to attract male audiences; the latter can dance along to create a more sensual atmosphere and usually give money to the dancers in exchange for kissing, touching, or even sex. From the point of view of other Sundanese, urang Karawang or Karawang people are 'more rude' in their attitudes and language.

Notes on methodology

This thesis makes use of the personal narratives of women and men – their ideas, feelings, experiences, and behavior as PLWHA or Odha. These narratives are complemented by my observation of their non-verbal gestures, silences, and expressions in different circumstances. Observation is particularly important to fully understand interviews in context. As in any ethnographic study,
establishing rapport is essential for creating trust to allow informants to speak openly – particularly regarding their seropositive status, a sensitive topic to disclose to others. Since my entry point into the lives of Odha was through Pantura Plus, an NGO which had established a support group for Odha, I encountered few difficulties finding informants and conducting interviews.

Pantura Plus was initially a support group run by the Jakarta-based NGO, YPI. YPI opened its first branch in Karawang town in 1998 after the first case of AIDS was found there in 1996. Pantura Plus was set up in 2004 to empower PLWHA to access health services and to take part in the HIV/AIDS control program. In 2006, Pantura Plus legally became an NGO in order to implement a harm reduction program among injecting drug users. This program was funded by Family Health International (FHI), a USAID-funded international NGO. During this research, Pantura Plus also obtained support from Badan Narkotika Nasional (National Narcotics Board) to conduct an anti-drugs campaign and lobbied the local government to improve health services for PLWHA.

Early interviews were carried out at the Pantura Plus office where many of my research participants gathered. Subsequent interviews took place in different locations, including informants’ homes, an eatery, the YPI village post, on public transport, and in workshops and meetings. When possible, I recorded the interviews with the consent of the interviewees. If the interview was not recorded, I immediately wrote field notes after the meeting.

My research relationships with some of the participants developed into friendships over time. Knowing that I came from the university, they often saw me as a source of information, especially concerning HIV. I was asked about ARV side-effects, the effects of a low CD4 count, medicines for opportunistic infections, the effects of taking ARVs and using drugs at the same time, etc. Some participants perhaps perceived me as a counselor. I felt awkward when I could not properly answer their questions, though I always suggested that they ask the right person – the physician or the counselor. A few participants asked me for direct help, usually to borrow money. My interactions with my informants thus produced

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2 CD4 cells are a type of white blood cell that fights infection. The CD4 count measures the number of CD4 cells in a blood sample to gauge the strength of one’s immune system. It indicates the stage of one’s illness, guides treatment, and predicts how one’s disease may progress.
anthropological knowledge in a more dialogical way than merely ‘extracting’ it (Spronk 2006:34).

Being male, married, non-Sundanese, over forty, and an academic influenced the research in particular ways. First, being an outsider provided space for participants to speak openly about their personal lives and problems, since they assumed I would not judge them according to their social norms. They called me ‘elder brother’, which meant they could ask my opinion on certain issues and expect me to provide advice.

Second, being a man made it easier for me to approach men than women; I needed more time to build rapport with women to be able to discuss their intimate experiences. Yet, perhaps the barrier was with me, as a male researcher cautious to avoid offence. Despite these constraints, the stories of female interlocutors are salient in this thesis. As for my male interlocutors, they seldom shared their intimate lives with other people. I found that men had greater difficulty showing their feelings, particularly regarding their drug addictions.

An important ethical issue in this research is confidentiality, not limited to the information I obtained from my interlocutors but also to their seropositive status. Every Odha has the right to disclose or not disclose their status to others. Since my entry was through an NGO that had launched a support group for Odha, I knew who was HIV-positive without them voluntarily disclosing it to me. Often I learnt someone’s seropositive status from others who deliberately or accidentally disclosed it, since they knew I was doing research on HIV/AIDS and considered me a trusted person. I maintained the confidentiality of my interlocutors’ seropositive status even to other Odha. In certain circumstances, I pretended not to know a person’s status unless he/she voluntarily disclosed it to me, even if I already knew from another source. Breaching confidentiality among Odha seemed an ordinary thing, however. They perceived it as internal to their own group, despite the fact that not all Odha agree on this issue.

I have used pseudonyms to protect my interlocutors, although a few had already publicly disclosed themselves as Odha. In certain passages, details have been removed or altered to further protect their identities. In presenting their life stories, I have, when necessary, used two or three different pseudonyms for a single interlocutor to protect his/her privacy.
Significance and limitations

This study fills the blank spot in our knowledge on the lives of marginalized PLWHA in West Java society, presenting how they negotiate their lives through silence, stigma, activism, marriage, care, and death. As an ethnographic study, it looks beyond the numbers and reveals how limited the figures are in explaining the socio-cultural context of the HIV/AIDS epidemic in Indonesia. Many AIDS deaths are not counted in national statistics; I thus strive to give a face to people living with HIV/AIDS – their rights, desires, practices, and confusion. I also try to convey how it feels to be an Odha: the options they face, the limitations they encounter, and how they live with the stigmatized illness.

I am aware that the limited number of case studies presented here does not facilitate comparison. Although a similar picture of the HIV/AIDS epidemic may emerge in different settings, this study only represents a certain cultural setting. Its findings are not intended to be generalized to other socio-cultural contexts.

Dissertation outline

This thesis consists of eight chapters. This first chapter has focused on the research questions as well as the theoretical and methodological considerations that direct this study.

Chapter 2 describes the evolution of HIV/AIDS policy in Indonesia, and its constraints and gaps in practice. I examine current policies by focusing on the contextual factors that affect policy-making and implementation. This chapter reviews the socio-cultural factors surrounding HIV/AIDS and reproductive health issues in Indonesia, and problematizes the ‘risk’ approach of current HIV/AIDS programs that focus on sex workers and condom use while failing to reach the majority of young men and women at risk of contracting HIV.

Chapter 3 addresses the context of the HIV/AIDS epidemic in Indonesia, focusing on Karawang district where I conducted my study. I examine the social, cultural, and political drivers of the
epidemic in Karawang society by focusing on prostitution, migrant workers, injecting drug users, and prisoners.

Chapter 4 presents the life stories of Odha to understand how they were infected, often without knowing that they were at risk. These accounts illustrate how self-stigma and silence prevent them from obtaining family support and care.

Chapter 5 examines how people living with HIV confront ill health and how their narratives of illness intersect with stigma, economic hardship, family support, and efforts to maintain their health.

Chapter 6 examines HIV within marriage. It describes the roles and responsibilities of spouses, their fertility desires, the difficulties of disclosure, and how couples negotiate risks within sexual practice.

Chapter 7 highlights the struggles of HIV-positive women in pregnancy and delivery. Through marriage and having children, HIV-positive women contest stigma from families and communities, and pave the way to normalcy in their lives.

The final concluding chapter reflects on the themes and issues raised in this study and places them in the wider context of Indonesian society.