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

The government of Indonesia has stated its aim to decrease the rate of new HIV cases as part of its commitment to achieving the Millennium Development Goals (MDGs) by 2015. Over the last two decades, the Indonesian government’s approach to HIV/AIDS control and prevention focusing on ‘high risk’ groups – sex workers and their clients, injecting drug users, men who have sex with men and male transgender – has been unable to change the trajectory of the epidemic.

Indonesia’s HIV/AIDS policy has evolved since its initial impulse to blame foreigners in the country. Due to the influence of NGOs, the first National Strategy (1994-2002) embraced a rights-based approach to control the epidemic, though implementation was hampered by conflicting interpretations among government institutions. Implementation lagged behind until early in the twenty-first century, when the number of HIV/AIDS cases skyrocketed. The second National Strategy (2003-2007) therefore aimed to establish a more comprehensive approach to fight the epidemic, with strong support from international donors.

The focus on high risk groups ignores the threat to the broader population; recent statistics show that more and more housewives are being infected by their husbands. This study found that many HIV-positive women learnt their serostatus during antenatal care, just before giving birth, when their children became severely ill with HIV-related illnesses, or when their husbands/partners suffered severe opportunistic infections. Most women were infected by husbands who were IDUs and/or engaging in unsafe sex without their knowledge.

A key constraint facing HIV/AIDS programs in Indonesia is the taboo on the public discussion of sexuality. Sex in Indonesian society has its legitimate place in marriage – and with the assumption of fidelity, marriage has been seen as a safe haven to avoid HIV infection. Nevertheless, the more recent increase in the number of HIV-positive pregnant women and children has forced PMTCT onto the agenda. Implemented through existing programs of antenatal care, PMTCT services in theory are now available to all women. Integrating HIV/AIDS within Indonesia’s reproductive health services poses new challenges for policy and programming. But again, implementation lags behind, in part due to the socio-cultural resistance of policy-makers to admit that marriage is no longer a safe haven. As the epidemic advances, blame, stigma, and denial are still coloring the responses of both government and society.
This ethnographic study conducted in Karawang district of West Java province, a rice granary rapidly turned into industrial area as I explained in chapter 3. Karawang district is spatially vulnerable to the spread of HIV due to its proximity to the north coast highway, the main East-West artery linking the big cities on Java. Large mobile populations of truckers, bus drivers and other motorists – the usual customers of sex workers – ply this highway. But more important is a structural driver of HIV epidemic in this district: pattern of marriage, long history of prostitution, mobility and migration, drugs use, and penitentiary system. These drivers intertwine each other which place everybody in Karawang district vulnerable to HIV infection.

In the chapter 4 I present life stories of four Odha (people living with HIV/AIDS). They are ordinary people who were unaware of the risks of HIV infection. Their stories show that young people in Indonesia are not receiving adequate information about HIV/AIDS, and that the lack of prevention initiatives among the general population makes family members of high risk individuals more vulnerable. Stigma and shame surrounding being an Odha are salient in these stories, forcing Odha to adopt tactics to avoid disclosure in their social relations. Their stories reflect how silent epidemic occured in Indonesia society.

Through illness narratives of Odha I argue that the intersection of ‘deep illness’, fear of stigma, the lack of family support, economic hardship, and fragmented healthcare leads to Odha precarious lives, which can result in death. Fear of stigma and disclosure are dominant themes in their narratives, along with fear of sickness, which is always linked to economic hardship. Disclosure to family members did not always result in stigmatization, as many Odha feared. Some cases revealed the significant roles played by family members and support groups in caring for Odha who had fallen ill. I also discuss the tactics developed by Odha to cope with economic hardship in their daily lives, how stigma and disclosure intertwine with social support from the family, and how economic hardship hinders access to healthcare. In addition, intertwining variables -- limited budget for HIV/AIDS service, poor coordination among related institutions, NGO’s dependency to international funding, economic hardship, self-stigma – cause a fragmented healthcare in Karawang district.

HIV/AIDS is not only an individual illness, but an illness of the family. The presence of HIV/AIDS has different consequences for different families, just as illness progressions differ. In the sixth
chapter I reveal aspects of the inequality between husbands and wives. As wives, as mothers, and often as breadwinners too, women shoulder most of the family responsibilities. Their HIV status does not affect relationships within the family. Men – whether they are HIV-positive or not – perceive themselves to be the heads of families, regardless of whether they fulfill their socially expected roles.

Fear of stigma and discrimination deter *Odha* from disclosing their seropositive status. In almost all the cases I came across, disclosure was limited to an inner circle of parents or siblings, a spouse or current sexual partner, one’s closest friends, peer group, or support group. In this chapter I also examine the problem of disclosure, particularly in the context of the spousal relationship, and how being HIV-positive influences one’s sexual and reproductive practices. Disclosing one’s HIV status can disrupt relationships. This is most obviously the case in the intimate relationships *Odha* have with lovers, partners, and spouses. Disclosing one’s identity as an *Odha* always involves interpretation and negotiation in different social contexts. Eventually, disclosure must be perceived as a process that requires gradual adjustment on the part of *Odha* vis-à-vis their spouse/partner, family, peer group, and community. The result of disclosing one’s HIV status remains uncertain. Some instances led to acceptance and support; others led to stigmatization, rejection, and blame. In a society where HIV/AIDS is highly stigmatized, silence and secrecy are common strategies for *Odha* to circumvent rejection and discrimination.

Motherhood is the socially sanctioned ideal for Indonesian women. Having children provides a woman with a social identity and guarantees her status in her family and kin group. For a man, marriage and having children are status symbols; he demonstrates his masculinity and virility and is recognized as the family head. Many *Odha* in this study revealed their intention to have children. The effectiveness of ARV treatment brings hope to many *Odha* to lead normal lives, from working to marriage to having offspring. The desire to have children coexists with worries of infection, concerns about one’s CD4 count, and a rights-based consciousness often encountered among networks of *Odha*.

Reproduction is a complex issue for *Odha*, particularly women. HIV-positive women face a string of reproductive choices: whether to get pregnant, the right time to do so, regarding abortion, antenatal care, caesarian versus normal delivery, breastfeeding versus formula milk, ARV treatment, and condom use as protection against re-infection. In this seventh chapter, I argue that pregnancy
and giving birth are ways for HIV-positive women to contest HIV/AIDS-related stigma in the family and community; through marriage and having children, they regain control over their reproductive lives and pave the way to ‘normalcy’. In navigating HIV in pregnancy and delivery, the role of NGOs and support groups is crucial, not only for disseminating up-to-date information but also for helping HIV-positive women access PMTCT services.

This study has traced the contours of a silent epidemic: how – in a country with a relatively low overall prevalence rate and significant social stigma surrounding HIV/AIDS – people are becoming infected without knowing they are at risk. Despite the enormous resources available at the global level for programs to prevent transmission from parents to children and to provide care and support to people living with HIV/AIDS, young people in Indonesia are still dying from AIDS. They are beyond the reach of the information that they so desperately need, and are unable to afford those services that are available.