Life and death with HIV/AIDS: life stories from Karawang, West Java
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Chapter 8

Conclusion

This study has focused on the everyday lives of PLWHA or *Odha* in Karawang district, West Java: how they cope with poverty and stigma, conduct their intimate relationships, marry, bear children, learn about their illness, hide or disclose their HIV status, become activists, care for each other, fall ill, and die. It has also directed attention to the factors fuelling the epidemic in Indonesia and government policies to contain it.

This study has aimed to fill a blank spot in our knowledge about the lives of marginalized *Odha* in West Java society. Its ethnographic approach looked beyond the figures provided by government statistics. Not only are such figures unable to explain the socio-cultural contexts of the HIV/AIDS epidemic in Indonesia; they also grossly under-report the problem. As an ethnographic study, my research was based not only on documents and reports, but on a detailed case study of one NGO – Pantura Plus – and the narratives of a small number of young, sexually active *Odha*, both men and women, whom I followed closely over a number of years. Through this, we saw the precarious lives of PLWHA in an industrializing rural and small town district in Indonesia, as well as the intersection of local, national, and global influences on their everyday practices.

Policies for HIV/AIDS prevention and control in Indonesia emphasize patients’ rights and partnerships between government, NGOs, community-based organizations, and other civil society stakeholders. While this may look promising on paper, the implementation of HIV/AIDS policy in the era of decentralization has suffered from lack of political commitment by local governments, poor coordination among stakeholders, and moral and religious conservatism surrounding sexuality – towards sex work, condom use, and sexual minorities.

The government-propagated notion of ‘marriage as a safe place’ is a false promise; cultural beliefs and practices related to gender and sexuality place married people in Indonesia at risk as well. Cultural prescriptions against behaviors that make adolescents vulnerable to HIV place this group in a particularly precarious
position, due to lack of both information and support. Fortunately, NGOs have stepped in to combat the epidemic, with support from international donors. The global players – e.g. UNAIDS, USAID, Ausaid, and the Global Fund – have had a significant influence on Indonesian government policy at both the national and local levels. Decentralization has given NGOs greater leeway to work with local governments.

The HIV/AIDS epidemic in Indonesia has now entered its ‘concentrated’ stage. Blame, stigma, and denial, however, still color the responses of the government and the general public. The fall of the authoritarian Soeharto regime in 1998 and the coming to power of a series of democratic governments in the so-called ‘Reform Era’ have not drastically changed society’s values regarding sexuality, though more NGOs are now active in the field. Poverty remains widespread.

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, and men who have sex with men – has been unable to change the trajectory of the epidemic. The focus on ‘high risk’ groups overlooks men in general, though we know that men are the bridge linking so-called ‘high risk’ and ‘low risk’ populations. Intervention programs in the lokalisasi, for instance, focus on female sex workers rather than their male clients, though we know that the latter have much greater power to negotiate condom use.

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. The failure of the ‘risk group paradigm’ in Indonesia is partly due to its use of ‘foreign’ terminology. The government and NGOs often unconsciously employ Western, academic notions of disease and risk without translating them into less abstract concepts comprehensible to those who are vulnerable to HIV. I suggest that there is a particular need to translate the notion of ‘risk’ into terms that are more culturally and socially accessible in the Indonesian context. Furthermore, people do not necessarily identify themselves with the designated ‘risk groups’ if, for example, they are in denial about their behavior.

This study was conducted in Karawang district, West Java, a region where numerous factors have contributed to the spread of the epidemic: industrialization, poverty, migration (both to surrounding
cities and abroad), marriage patterns, prostitution, and proximity to the northern highway. These factors have heightened risks for certain sub-populations, including injecting drug users, sex workers and their clients, migrant workers (mainly women), and prison inmates. The case of Karawang district also reveals the epidemic’s transmission routes into the general population.

The consequences for adequate healthcare provision are serious. The under-reporting of AIDS cases, the unpreparedness of the health services to deal with HIV/AIDS, and discrimination towards Odha by healthcare providers all undermine adequate and effective care. The fragmented healthcare system in Karawang, its slow response to the needs of Odha, limited budgets, the weak role of the Local AIDS Commission, NGOs’ continued dependence on external (international) funding, and widespread poverty all intertwine to lead to the premature and preventable deaths of Odha.

Many Indonesians are unaware of the risks of HIV infection. The life stories of the Odha in this study show that adequate information is not reaching the general population, particularly adolescents. The stigma of being an Odha and tactics to avoid disclosure in their social and sexual relationships were salient in their stories. Many women in this study – particularly those who were most likely infected by their husbands – found out their seropositive status only when they or their husbands and children became severely ill.

The life stories told by the Odha in this study focused on fear of stigma, lack of family support, economic hardship, ignorance about their medical condition and the risks of transmission, and difficulties accessing adequate healthcare. The stories revealed the precariousness of their lives, often ending in deaths that might have been prevented under more auspicious circumstances. Access to ARV medicines was limited by the government’s erratic supply. Adherence to ARV therapy was a challenge for those still addicted to drugs. The dynamics of stigma and (fear of) disclosure, bodily illness, and economic hardship all cast a shadow over their daily lives.

The self-stigma of Odha was salient, only gradually diminishing through disclosure. The notion of disclosure has largely been popularized by NGOs and other support groups where Odha learn about their illness. But in societies such as Indonesia, where HIV/AIDS is enshrouded in social stigma, silence and secrecy
remain common. Disclosure is a social process; its impact is often hard to predict. But contrary to their fears, some of the Odha in this study were accepted by their families. In some cases, families and support groups played key roles in caring for Odha who had fallen sick or were dying. Other stories, however, revealed experiences of stigmatization, rejection, and blame.

Stigma, silence, and ambiguity were also recurring themes within spousal relationships, among both HIV discordant and concordant couples. Many of the Odha in this study, as they were still young, desired to have children. But they lacked adequate information on the prevention of mother-to-child transmission of HIV. They also lacked information on technicalities such as the CD4 count, ARV treatment, and caesarean delivery. Unfortunately, existing NGOs do not address the issue of Odha wanting to raise families. People struggling with these kinds of questions do not have enough information – and often also lack the financial means – to make informed decisions.

Access to PMTCT services is crucial for HIV-positive women. As the services available in urban centers are prohibitively expensive, the Odha in this study had to make use of their social networks – friends, NGOs, and support groups – to secure safe deliveries and to prevent the vertical transmission of HIV. In navigating HIV in pregnancy and delivery, the role of NGOs and support groups proved indispensable – not only for disseminating up to date information, but for helping Odha access PMTCT services. The reliance on international funding agencies, however, makes the availability of PMTCT services, even in urban areas, highly uncertain.

This research also revealed cases of the post-partum sterilization of HIV-positive women by physicians, consistent with findings in others countries such as Thailand and Brazil. Although there was – in theory – consent from patients, their ‘decisions’ were strongly influenced by medical professionals, while patients were not well informed about sterilization. This is a hitherto under-addressed issue regarding the reproductive rights of Odha in Indonesia.

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.