

Lives endangered



Three stories of people with HIV/AIDS in the central highlands of Papua show that both the government and community have a long way to go in confronting this major epidemic

Carole Reckinger and Antoine Lemaire



This 15 year old girl has been suffering from a rash all over her body since she started ARV therapy nine months ago. *Carole Reckinger*

The sun has chased away the morning chill in the small town of Wamena in the Papuan central highlands. Fifteen year old Magda (not her real name; all names have been changed in this article) is taking her first walk outside the hospital ward in two months. She is still very weak and needs the help of her mother for every step she takes. Two months ago, Magda came to hospital in a critical condition, having lost a lot of weight, and being unable to eat. She tested HIV positive and is still taking antibiotics to fight the opportunistic diseases affecting her before she can start the anti-retroviral (ARV) treatment. Her mother has been sitting by her bed day and night with eyes red from crying, dreading the day she will lose the last of her children to the virus. Magda's two sisters and younger brother have already died, and her mother and uncle have also tested HIV positive.

Magda is in pain, but she is also very bored. The bright young girl has no leisure activities, or anything to take her mind off her situation. The hospital environment itself is also taking a heavy toll on her health. The place is filthy, she lies in a room with seven other patients, most of them terminally ill. She has witnessed a few deaths already. The smell coming from the toilets is unbearable and there has not been any running water for the past three weeks. Understandably, Magda is reluctant to use the bathroom and complains of her complete loss of appetite. Despite taking her medicine regularly, she is rapidly losing weight.

Like many Papuans, Magda didn't test voluntarily for HIV, but came to hospital when she was already at an advanced stage of AIDS. In Papua, people often only seek medical attention when it is impossible to walk or work. HIV/AIDS is also a new disease in the region, and most people are still unaware of its modes of transmission and consequences. Voluntary Counseling and Testing (VCT) only started in 2007 in Wamena, despite the fact that the first case of HIV in Papua was discovered in Merauke in 1992.

A Papuan epidemic

A church sponsored clinic, Klinik Kalvari, took the lead and started testing, which led to the public clinics and the hospital offering the service shortly afterwards. During the first year, at Klinik Kalvari, 21 patients tested positive, a number which

increased dramatically every year to reach 196 cases in 2012. The latest statistics, from September 2012, show that 2504 people in the Jayawijaya region have tested HIV positive (with a population of over 200,000). An NGO worker estimates that by February 2013, the number had reached 2700.

Such figures, however, are only the tip of the iceberg. The number of people who are infected with HIV but are unaware of their condition is much higher and can only be guessed at. Local NGOs estimate there are at least 6000 undetected cases in Jayawijaya and surrounding areas alone.

The two provinces of Papua and West Papua are the worst affected by a growing HIV/AIDS epidemic in Indonesia. The country saw the HIV incidence rate, i.e. the number of new infections per year, increase by 25 per cent between 2001 and 2011. UNAIDS reports that 380,000 people are living with HIV across the country, with Papua and West Papua provinces showing the highest occurrence rates. With over 13,000 people having tested HIV positive in both provinces, Papua has an HIV prevalence rate of approximately 3.5 per cent, eleven times higher than the national average. In 2006, AusAid predicted 3.61 per cent of the population in Papua would be HIV positive by 2025. This level was reached more than ten years earlier than predicted.

Disease, education and politics

Marta (19) rocks her four-week-old baby while chatting to her siblings. One of her eyes is black and swollen. Her sister tells us it is the consequence of a drunken fight with her husband. She adds this is not unusual in the family. Marta and her husband share a small house with her father, who is known to have multiple partners, her two sisters and one brother. Marta's whole family, apart from her grandmother, is undergoing ARV therapy. Marta tested HIV positive over two years ago but didn't tell her boyfriend about her status when she met him, and he tested positive a few months later.

When she became pregnant, his family pressured them to get married. She takes her medicine most days, but sometimes forgets and is only reminded when she starts feeling weak. Her son can only be tested when he is over 18 months old, but Marta is careful to feed him only milk formula, advice she got from a local NGO. There are currently 241 known cases of transmission from mother to child in both provinces.

The prevalence rate among ethnic Papuans is almost twice as high as among migrants from other parts of Indonesia. Contrary to the rest of Indonesia where the epidemic is mainly concentrated among high risk groups such as injecting drug users and sex workers, in Papua transmission is almost entirely through heterosexual sex, and has very much spread to the general population. Sexual relations were previously controlled by social norms and taboos, which have been severely eroded by the loss of cultural identity. Youth now have casual sex on a very frequent basis, defying parental authority. This has been seen as a way of expressing agency in a society where opportunities for Papuan youth are very rare. The Indonesian authorities, such as teachers and others in positions of power, view these practices of casual sex as a cultural practice, but in fact it is was likely very rare prior to the arrival of the churches and the Indonesian occupation.

The exclusion of large parts of the indigenous populations from development and the market economy has also led increasing numbers of Papuans to engage in prostitution. Poverty is such that transactions often take place in unregulated open air or street dwelling sites with no safety precautions. One NGO worker said that some very young girls sell their bodies for under 50 cents, less than the price of a packet of cigarettes or condoms. By now the virus has spread to even the furthest villages, and some women who have never left their home village, several days' walks from the closest urban centre, have been tested positive.

Transmigration and large resource extraction projects have fed the sex industry, which has also been a major driver of the spread of the disease. Mimika, where the large Freeport McMoran gold and copper mine is based, the incidence rate is one of the highest in the province.

The rapid spread of the disease is compounded by a lack of knowledge about sexual health and misconceptions about the virus. When senior high school students were asked about HIV/AIDS modes of transmission during one of the rare awareness-raising workshops held by a local NGO, a majority of them stated that the virus was transmitted through mosquitoes. They were also not aware that no cure for the disease has yet been found. A worrying number of youngsters also believed that the virus could be transmitted through kissing and shaking hands.

A lack of knowledge about the modes of transmission, coupled with the long running political conflict and the climate of mistrust and fear it has created, has led to many misconceptions and a number of conspiracy theories. The belief that the government, the military or other outsiders have introduced HIV in order to decimate the indigenous population is widespread. A common belief among highland Papuans is that chicken served in restaurants (mostly run by non-Papuans) is injected with the HIV virus to intentionally infect them. This suspicion was even shared to the authors by educated, highly respected members of the Papuan Customary Council (DAP). These misconceptions about the virus have a direct impact on the lives and welfare of people living with HIV/AIDS. Many Papuans are suspicious of awareness raising campaigns conducted by Indonesians and some are even reluctant to visit hospitals staffed with Indonesian nurses and doctors.

Keeping a secret

Yoli (23) looks strong and healthy as he comes down the hill carrying his chainsaw. The pig pens in his village compound are all empty, and only a couple of chicken scratch the ground looking for insects. Yoli's father, the village head, organised a big feast for Yoli's wedding a month ago. Yoli used to study agriculture at a university outside Papua until he fell ill and had to come back home. Weighing only 30 kilograms, he was diagnosed as HIV positive. His father supported him from the

moment they learned the diagnosis, but father and son decided to keep it a secret.

Taking his medicine regularly, Yoli is strong and healthy and his young wife does not know about his condition. Yoli wants to tell her but is scared she will leave him when she finds out the truth. 'If people in my community knew of my status, horrible things could happen' he confides.

People known to be infected with HIV are not at risk of being burned alive anymore, as was the case some years ago, but the stigma is still strong. Some priests claim during mass that AIDS is a punishment from God to those who have sinned. Churches are slow to tackle the problem, and it can still be difficult to find a priest who will bury someone who is known to have died from an AIDS related disease. A young NGO worker who studied theology tells us that he sometimes spends many days looking for priests to perform funerals for HIV patients, knocking on many closed doors and being turned back.

The fear of stigmatisation in the community stops people from sharing their experiences and makes them reluctant to get tested for the disease. But testing is only the first step. Once diagnosed, many people do not take their medicine. Some decide to try traditional remedies such as the fruit of the Pandanus tree, and perform traditional rituals to try and cure the disease. Others start taking the medicine but don't take it regularly, or stop taking it once they feel better, as for many treatment equals cure. Others take their medicine regularly as long as they are in town, but stop once they return to their village, as they have to return to town to receive new supplies of medicine but cannot always afford the transport fee.

The stories of Yoli, Marta and Magda are but three of the many stories of people living with HIV/AIDS in Wamena. To fight the epidemic, a handful of NGOs are working to raise awareness, get more people tested, help patients and work towards decreasing stigma. The severity of the situation, however, has been completely underestimated by the local authorities. So far, their response to the epidemic has been inadequate. Large amounts of money have been injected into programs that provide awareness raising and poster campaigns, but with minimal monitoring and preliminary research.

Moreover, special programs face an uphill battle when the surrounding health infrastructure is so weak. The complete lack of health services and education in many parts of rural Papua, and their poor quality in the places they do exist, not only facilitate the spread of the disease, they also severely impede any efficient response to the epidemic. Thus, although the provincial governments have made HIV testing and treatment free, many Papuans do not have access to health care or education services at all, and are thus unlikely to be reached by awareness raising campaigns any time soon. And in the meantime, the virus continues its deadly advance into the highlands. One of the latest victims is Magda, whose story began this article, but who died a few weeks after we met her in the hospital. Like that of every person who has died in Papua from what should be a controllable disease, her death was not only a terrible tragedy, but also an indictment of the failure of the outside world, and the authorities.

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