

Minority women's
vulnerability to
HIV/AIDS in
South East Asia

Nicole Girard

Mar Yee first learned she had been infected with HIV in 2005. Pregnant and away from her home in Karen State, Burma, Mar Yee had few health care options. In Burma, health care infrastructure is extremely poor, lacking even basic facilities and equipment, strained after years of civil war in many areas of the country that are home to ethnic minority populations. Mar Yee, like many others from her Karen ethnic group, fled to Thailand in search of the opportunities and stability that she simply couldn't find at home. By her early 20s, she was living with a man who gave her enough money to support herself in return for sexual favours. It was this man, she suspects, who gave her HIV. After she grew tired of the lack of any emotional bond, she dated another man, with whom she eventually got pregnant. As an undocumented migrant in Thailand, there were no public health options available to Mar Yee. She, like thousands of other women who find themselves in the margins between Thailand and Burma, had to depend on an NGO clinic for antenatal care, where HIV testing is part of their services.

In South East Asia, many women from minority and indigenous communities have similar stories to tell. But that does not mean their stories have been included in the official accounts of women living with HIV in South East Asia. In fact, in a region that has the second highest HIV rate after Africa, as well as the highest numbers of indigenous peoples (an estimated two-thirds of the world's indigenous population lives in Asia), the struggle of indigenous and minority women and their right to health remains largely invisible.

UNAIDS estimates that there are about 1.2 million people living with HIV/AIDS in South East Asia, 37 per cent of whom are women. The countries with the highest number of people living with HIV/AIDS are Burma and Cambodia, Indonesia and Thailand. Unfortunately, the experiences and vulnerabilities of women belonging to minority and indigenous groups are lost in these numbers; there are no official figures for HIV rates for minority and indigenous women or men.

HIV interventions in South East Asia have largely focused on groups considered high-risk, including sex workers, men who have sex with men, and people who inject drugs, whose rates

have been increasing, as opposed to the general population. Female partners of men who use sex workers or intravenous drugs are also an increasingly acknowledged at-risk group. But the focus on these specific at-risk groups can ignore those who are vulnerable to contracting HIV or are denied access to services because of systemic discrimination along ethnic, religious and linguistic lines.

And there is reason to be concerned. Although UNAIDS states that 'no country in the region has a generalized epidemic' (when HIV prevalence is 1 per cent or more in the general population), in some areas where minority and indigenous populations reside, HIV prevalence has reached a generalized epidemic. For example, in the highland provinces of Papua, Indonesia,¹ HIV is spread mainly through heterosexual transmission. Gender-based disparities mean that married women often have little say with regard to condom use; the epidemic therefore threatens to disproportionately affect indigenous women living in those areas.

The cases from Thailand and Burma, Vietnam and Papua described below show that some minority and indigenous women in South East Asia have a higher risk of contracting HIV/AIDS and are not receiving the treatment they need. These women are particularly vulnerable for a range of factors: gender inequality, ethnic discrimination, unequal access to health care and education, conflict and associated human rights abuses in the areas they live, and poverty and lack of opportunities. Although there is little data on HIV prevalence rates among minorities and indigenous peoples generally, and minority and indigenous women in particular, international organizations, government and health care professionals must be more aware of the issues affecting women from minority and indigenous communities, and how to address their particular needs.

Papua, Indonesia

*'A lot happens in society, where women who don't know anything in the end contract HIV/AIDS because of their husbands' "snacks" outside [the home]. They get cash from Special Autonomy funds, then in a matter of days use it up paying prostitutes and buying liquor.'*²



Papua was forcibly incorporated into the Indonesian state in 1969 and since then its people have struggled to realize their rights in the face of militarization and conflict, mass in-migration of Indonesians from other areas of the country, and development projects that leave little money in the hands of Papua's indigenous people. The 2001 Special Autonomy law was intended to give the province more fiscal and administrative autonomy, but many of its provisions remain unimplemented.

HIV infection rates in Papua are 15 times the national average, but since the government does not collect data disaggregated by ethnicity, this figure obscures how hard indigenous Papuans are hit. In 2008, UNAIDS estimated that the HIV prevalence rate was 2.4 per cent among the general population, but reached 3.4 per cent in the indigenous Papuan populated highlands.³ Some experts estimate that prevalence rates are as high as 7 per cent to 10 per cent in the highlands.⁴ The epidemic is driven largely by heterosexual transmission. Over 50 per cent of the Papuan population have not heard of HIV or AIDs and 65 per cent do not know that a condom can prevent its transmission, according to government data from 2007.⁵

The area with the fastest-growing HIV rates

in Papua is Mimika, home to the giant Grasberg copper and gold mine. In 2012 alone, there were 367 new cases recorded in Mimika, reaching a total of 3,190 cases since the first HIV cases were identified in 1996. HIV infection rates are particularly high around mining sites, military bases, ports and other transport hubs, where men come for work and thousands of female sex workers, both Papuan and non-Papuan, have followed.

Many Papuan women live a transient existence, which can make them more vulnerable to infection. According to Jenny Munroe, a researcher at the department of community health sciences at the University of Calgary:

'Men and women get together young ... and the woman is taking care of the household and the children while he is off getting higher education or working. They move around, so many women are in some in-between place, not where they are from, and yet not always with their husband either, as he moves from place to place pursuing opportunities, and starting new sexual/marital relationships in new places. Gender expectations, marital norms and new mobilities are certainly posing challenges for young women in terms of HIV exposure.'

Married women are most at risk for contracting

Left: An indigenous Mooi woman, Papua, Indonesia. *James Morgan/Panos.*

HIV in Papua, according to official data. Papuan women experience a high level of domestic violence. The number of cases of violence against women in Papua was the highest in Indonesia, according to a 2006 national survey.⁶ Papuan women's groups reported an increase in domestic violence after the implementation of the Special Autonomy law of 2001, a provision of which disburses central government funds directly to households. Many Papuan women report their husbands taking the money and spending it on alcohol and sex workers. Women do not feel in a position to demand fidelity or ask their husbands to use condoms, even if they know their partner is infected with HIV.

Papuan women who engage in sex work are at an even higher risk of HIV infection. The industry is stratified by ethnicity; migrants from other parts of Indonesia are the highest paid and work in the relative safety of bars and brothels, Papuans are paid the least and work in the street, increasing the risk to their personal safety. Papuan women sex workers are also less likely to use a condom. In one rural area, an NGO study found that less than 5 per cent of Papuan sex workers used a condom. In comparison, Indonesian sex workers working in larger brothels outside the capital reportedly convinced 70 per cent of their clients to wear a condom.

Such low condom use and knowledge about HIV is a result of poorly targeted HIV education campaigns. For example, 100 per cent condom use campaigns have targeted brothels and bars, where mainly non-Papuans work, but have overlooked Papuans working outside these establishments.

There are also serious barriers for Papuan women to access health care. In Merauke, a town with one of the region's highest number of HIV cases, a government clinic provides free monthly medical check-ups for sex workers. In September 2001, 172 women used the clinic's services. But even though there are around 400 active female Papuan sex workers in the area, only one Papuan woman visited the clinic over a year. Reflecting a widespread tendency to blame Papuan indigenous culture, the clinic director argued that Papuan

women did not visit the clinic because of 'shyness' and their communities' overly 'strong' traditions. Other researchers suggest Papuan women do not know about the services offered or about HIV in general and feel intimidated by using a clinic run by non-Papuans.

Fear of stigma and discrimination

Papuans living with HIV face huge stigma and discrimination from members of their community; as a result many are afraid to be tested for HIV or get treatment. In highland communities, people commonly respond to illness by retreating to the forest to suffer the illness alone without access to care; this reinforces the idea that social withdrawal is an appropriate action. Self-stigma or a sense of shame is also common. Women take great care not to disclose their HIV status for fear it will threaten their relations with their family, especially as their physical well-being decreases.

Many women also do not access the care they need because they are afraid to disclose their status and have feelings of self-stigma. As one Papuan woman noted:

'I'm shy, I'm afraid if anyone knows my status. I heard on the radio that if you have HIV then you will die. So I don't want to tell anyone, I'm afraid. So I pretty much stay home, if anyone sees me they will suspect I have HIV.'

Many women feel judged by non-indigenous health care workers. A survey of health care workers in the highlands of Papua showed that some agreed with discriminatory statements such as that people living with HIV/AIDS are dirty and should be shunned; and most assumed that people living with HIV/AIDS will feel ashamed of their status.

Vietnam

The Vietnamese government collects some health data disaggregated by ethnicity, but only for the five largest minority groups, and not for HIV/AIDS prevalence, which is only collected on the basis of provincial prevalence rates. Vietnam's ethnic minorities comprise about 14.3 per cent of the population. The northern province of Dien Bien is home to 21 ethnic groups and the

majority Kinh here only make up 19 per cent of the population. In 2009 the province had the third highest HIV prevalence rate in the country, nearly three times higher than the national average.⁷

As in the rest of the country, HIV is concentrated among men who inject drugs, but in Dien Bien the HIV prevalence rate among men who inject drugs is twice the national average, reaching 43 per cent. Female sex workers, many of whom are local minorities, have an HIV prevalence rate of 20 per cent, which is the highest in the whole country. Further, HIV rates among women accessing antenatal care services in rural Dien Bien were 10 times higher than the national average, at 2.25 per cent.

People who inject drugs in Dien Bien, all of whom were male, had a significantly greater knowledge of how HIV is transmitted than the female sex workers, according to a report by the Asian Development Bank (ADB) and Vietnam and Laos government research organizations. The researchers attribute this to HIV campaigns that focus heavily on male drug users and which have perpetuated the notion that HIV is mostly the problem of injecting drug users. This tendency has led to what some are calling a 'hidden HIV epidemic' among the women of Vietnam, as many wives of drug users have not been accounted for, especially among minority groups. Most HIV-positive pregnant women and mothers in Vietnam have contracted it through their PWID (people who inject drugs) husbands and learned of their husband's status only after they were married.

Economic reforms in the 1990s increased cross-border trade while also indirectly facilitating heroin trafficking routes. Many minority groups in Vietnam have a history of traditional opium smoking among older men that, since the late 1990s, has turned into injecting heroin among younger men. Wives of men who inject drugs are at an increased risk of HIV, which is especially true of minority groups where high numbers of people inject drugs. In studies conducted in three Black Thai communities in Dien Bien, almost half of all women reported at least one male family member had used or was using heroin; a quarter reported at least one male family member dying from drug use.

Right: A Burmese woman in a safe house for women with HIV, Thailand. *Nic Dunlop/Panos.*

Ethnic minority women are less likely to receive treatment for HIV. This is reflected by their low utilization of antenatal care and health facility delivery services, and lack of knowledge about HIV and its transmission, compared to their Kinh counterparts. According to the World Health Organization (WHO), the disparities in access to health services for marginalized minority women and the social majority actually grew over the period of 2006 to 2010. Ethnic minority women are more likely to give birth at home and maternal mortality among minorities is four times higher than among the majority Kinh. Low use of health services makes it extremely difficult to prevent mother-to-child HIV transmission.

Furthermore, HIV tests are only available at district- or provincial-level health facilities. Many minority women receive antenatal care at community health centres, which do not offer HIV testing. Of those minority women who accessed antenatal services at district- or provincial-level clinics where HIV testing was available, only one-third were actually tested for HIV.

Geographical remoteness is often cited as the reason why minority women do not access health care, but health practices that do not consider the realities of minorities are also a significant barrier. For example, health care staff insist that minority women give birth lying down, rather than in a traditional squatting position, common for many minorities. Husbands are not allowed into the birthing room, as is customary for Black Thais and Hmong. Health attendants are often Kinh and so language poses difficulties for minority women, including for HIV voluntary counselling in provincial hospitals where few staff speak minority languages. Stigma in the health care system also prevents HIV-positive ethnic minority women from accessing services:

'We have to wait for all "normal" patients to be examined and receive then our turns, all remaining as people living with HIV and AIDS, to receive services. Doctors and nurses often treated us with bad-mannered behaviours.'



Borders of Burma and Thailand

The health situations facing ethnic minority and indigenous women from Burma and Thailand have many similarities, stemming from systematic human rights abuses, sporadic or non-existent access to health care, low education levels and few employment opportunities. Women from Burma migrate to Thailand in search of work and better lives, but migration leaves them vulnerable to a wide range of human rights violations; many are undocumented migrants, which leaves them at increased risk of sexual violence and exploitation. Many of Thailand's indigenous peoples still remain without access to citizenship documentation, barring them from access to Thailand's public health and education programmes.

Burma is experiencing a whole host of transformations as it makes moves away from a military-run administration, but according to many working in the ethnic minority areas, these changes have not been seen on the ground.

According to Dr Voravit Suwanvanichkij, a

researcher with Johns Hopkins Bloomberg School of Public Health working on HIV with border minority communities, the situation for Burma's minorities may actually be getting worse:

'Sadly, and ironically, the changes in Burma have resulted in more displacement and even multiple displacements, increasingly as a result of "development" projects that push people off their land. Ceasefires with ethnic-based armies have not resulted yet in a durable peace on the ground, and humanitarian groups still do not have full access to populations most severely affected.'

Decades of conflict, government mismanagement and serious under-spending on health infrastructure have left Burma's minorities with some of the country's worst health outcomes. The Mae Tao Clinic, a health facility on the Thai-Burma border serving people from Burma and its migrating communities, has seen a definitive increase in the rates of HIV in the last

10 years, from around 1 to 2 per cent prevalence rate.

There are no clear statistics on HIV rates among minorities from Burma or Thailand. Estimates coming from Burma are likely to be skewed, as HIV projections are based on very limited data, mostly taken from cities. Very serious problems have been reported on the borders of Kachin and Shan states, where ethnic armies have been in open conflict with the military for decades. Sentinel HIV testing of groups on the Thai–Burma border in the early 2000s has found an HIV prevalence rate among ethnic Shan to be 3 per cent for women and 9 per cent for men. In 1999, Shan migrant workers in Chiang Mai area had prevalence rates of 3.8 per cent for women, and 5.7 for men – double Thai rates at that time. Shan migrants’ rights are particularly at risk as they are not recognized by the Thai government as refugees, as opposed to their Karen and Karrenni counterparts, who have access to refugee camps on the borders.

According to Empower Foundation, a Thailand-based sex workers’ rights organization, for many women from Burma’s ethnic minority groups in bordering states, it is not a question of *if* they will migrate to Thailand, but *when*. Migration is unsafe: many lack identity documents from Burma, as travelling the long distance to the capital Yangon makes little sense. Many rely on human smugglers to try to ensure their safe passage, as women under 25 are not allowed to travel unaccompanied in border areas in Burma, and immigration and police on the Thai side of the border pose threats to their passage.

Once women find work they are paid less in the informal sector under poor working conditions – most often in agriculture, fisheries processing, construction and restaurants – with little freedom of movement. Thailand does have a migrant worker registration programme, which should give opportunities for health care, but many employers do not register employees, or women are not covered by the programme, as is the case for sex workers. Anti-trafficking legislation has only served to pose problems for sex workers as many were not actually trafficked: most of the women interviewed by Empower consented to their work. Women are imprisoned

for long periods of time under the law and eventually deported. Many are returned to areas plagued by conflict, areas known for abuses and systemic rape by Burma government forces against minority women.

Minority women from Burma and Thailand are at acute risk of HIV infection because of their engagement in low-end sex work with men who refuse to wear condoms, because Thai-language HIV campaigns do not reach them and because they have no access to health care and fear of seeking out health care services. Further, anti-retroviral (ARV) medication is hard to access: ‘In Thailand, for Thai women, there is universal health care and ARV,’ an Empower staff member notes, ‘but for undocumented migrants from Burma, they have no right to the health care. And they can’t go home to receive treatment either. You can’t carry your bed home ...’

‘The most marginalized are invisible. We don’t see them’, Dr Voravit

Looking at the situations of minority and indigenous women in Papua, Indonesia, Vietnam and Burma, there is a clear set of risks that make these women particularly vulnerable to HIV and, without access to health care, vulnerable to developing AIDS. But minority and indigenous women are largely overlooked by HIV prevention and care efforts because of their marginalized position. They are economically disadvantaged, with low education levels, low ability in the language of the majority, and face discrimination as women within their communities and discrimination from the wider society because of their minority or indigenous status.

With prevalence rates in some minority and indigenous areas reaching generalized epidemics, states and international agencies can no longer ignore the issues and must address the needs of these communities. What follows are some examples of initiatives that have successfully reached out to minority and indigenous populations, including women, for HIV prevention and treatment.

Klinik Kalvary: Indigenous-led community health clinic in Papua, Indonesia

Klinik Kalvary, a community health clinic started

by an American doctor, works in Wamena, Papua Indonesia. It is a grassroots organization, and all of its 20 staff are indigenous Papuans. When it first opened in 2006, they were overrun by indigenous clients wanting to get tested for HIV who had been too afraid to go to the hospital or other voluntary counselling and testing sites.

According to Marcel Kooijmans, who works at the clinic, the indigenous staff make all the decisions and are in charge of all of the programmes:

'They know the culture and also speak the local languages. We use contextualized examples to explain diseases such as HIV/AIDS. Women are still difficult to reach, so we are now developing programmes to specifically reach the women.'

The services of the clinic are available to everyone, but most of the patients are indigenous Papuans.

The clinic specializes in sexually transmitted diseases, tuberculosis, malaria and HIV/AIDS. It also researches ways to make services more accessible to Papuans, and advocates for a better health care system throughout Papua.

While the clinic offers free HIV testing and ARV treatment, it still faces funding shortages. 'We work together with NGOs who teach the local community,' Marcel explained:

'We go out with a testing team to places in the inlands [highlands]. Before we go, the people are taught about HIV and we always take counsellors with us. Before testing in and outside the clinic people get information about the test and HIV. Patients come back every month for check up and more information.'

The clinic also trains indigenous nurses for one year, who then go to work or open other clinics. They train people to live in the villages and directly care for and monitor those affected with HIV, and bring them to the Klinik for further help if needed.

'In everything we do we connect with the indigenous people. The local people know that our staff is local too and that is one of the reasons they like to come.'

The Sunflower Network: Peer support for ethnic minority women in Vietnam

The Sunflower Network started as a small group of HIV-positive women in Hanoi in 2004. It has since grown into a countrywide network of peer support groups, covering seven provinces with over 2,500 members. The network was initially supported by the Medical Committee Netherlands-Vietnam (MCNV). In 2009, groups were established in rural areas with high numbers of ethnic minorities, such as Dien Bien, recognizing the need for peer support among ethnic minority women.

The Sunflower Network's main objective is to improve the quality of life of pregnant women and mothers living with HIV, their children and families, by improving access to HIV treatment and providing information about HIV and its treatment to women, especially young women. The groups also work with national-, provincial- and district-level agencies to improve their understanding of the illness, and address stigma attached to people living with HIV/AIDS and the specific issues faced by women. Mobile voluntary counselling and testing clinics for pregnant women in rural minority areas has also been a key part of the network's work.

MCNV project manager Ian Brommage reflected on the project:

'The aim of this work is to help empower these women to advocate for their rights, ensure they have access to services and are able to live in their communities free from stigma and discrimination.'

In Dien Bien the Sunflower Network has established three project sites, with 212 members, many from the Black Thai community. As a result communities have seen improvements in mental health, improved access to services and knowledge of sexual and reproductive health. A recent evaluation concluded that stigma and discrimination against minority women with HIV/AIDS had decreased in health care and education, as well as from within their families and communities. This has been brought about through support to individual minority women with HIV/AIDS suffering stigma, as well as by organizing community events, which have helped

to strengthen their self-esteem and increase awareness more generally.

The Sunflower Network continues as a positive example of women peer support groups, and has resulted in spin-off groups, such as the Cactus-Blossom group for female injecting drug users.

Community radio drama spreads public health information in the Mekong region

'While good information does not guarantee good choices, no information virtually guarantees bad choices.' David Feingold, former UNESCO project manager

The key problem in providing effective HIV prevention among minority communities in South East Asia is that minorities receive virtually no HIV prevention information in their own language, according to David Feingold, former UNESCO programme manager. Between 2001 and 2011, UNESCO, with support from the ADB, undertook a project to disseminate HIV prevention information in minority languages throughout the Greater Mekong Subregion (GMS), which covers Cambodia, China, Laos and Thailand. UNESCO developed radio dramas to broadcast culturally appropriate information about HIV prevention in minority languages on local stations. In China, for example, the little HIV prevention material that was available in local languages had previously been directly translated from materials developed in Beijing. Characters were set in an urban context, using words and sayings relevant to a Han Chinese target audience; the cultural cues and signs inherent in the message were lost on minority populations.

In contrast, UNESCO developed a way of using storytelling to disseminate HIV information. Episodes were based on research undertaken in the communities, to develop believable storylines. Often storylines were written by a team of story writers from the minority community, or, when this was not possible, authors who were native speakers of the minority language. Dramas were then written in the minority language, rather than translated from Mandarin. After that, the minority language script was translated into the majority language

or English to double-check the accuracy of the health information. Programmes were then tried out with the local community to receive their feedback.

UNESCO's project is the only one of its kind that has addressed the issue from a regional perspective, understanding that the issue of HIV is very much a cross-border problem, particularly in the GMS. In total, the project covered 13 minority languages, and two were turned into television dramas.

'Women from minority groups are less likely to have good control of the national language, so this was one of the best ways to specifically engage minority women,' Feingold concluded.

Recommendations

International organizations and all levels of government must:

- acknowledge that women from indigenous and minority communities are vulnerable to contracting HIV/AIDS and experience significant barriers to receiving effective health care;
- collect data disaggregated by ethnicity and gender to target health initiatives toward the most vulnerable groups;
- acknowledge and remedy inequalities in access to health care, and incorporate a broader view of the multiple forms of discrimination faced by indigenous and minority women, and consider the role of men in preventing transmission among their partners and children;
- incorporate indigenous and minority women's voices, values and ideas into policy-making and programmes for HIV prevention and treatment;
- support grassroots initiatives that address the needs of minority and indigenous women;
- develop culturally appropriate material to raise awareness about HIV prevention in minority languages that is gender sensitive and targeted toward women; and
- prioritize education and training for indigenous and minority women health care workers, fostering full participation in health care administration and policy development. ■

Endnotes

1. Munro, J. and Butt, L. (2012) 'Compelling evidence: research methods, HIV/AIDS, and politics in Papua, Indonesia', *Asia Pacific Journal of Anthropology*, vol. 13, no. 4, 2012, pp. 334–51, retrieved June 2013, <http://dx.doi.org/10.1080/14442213.2012.694467>. Papua here refers to both Papua and West Papua, Indonesia.
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4. See: Butt, L. et al., *Stigma and HIV/AIDS in Highlands Papua*, retrieved July 2013, <http://www.papuaweb.org/dlib/tema/hiv-aids/butt-morin-et-al-2010-stigma-HIV.pdf>
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