
TREAT Asia Report

AIDS Education Competes With Tradition in Papua—An Interview with Ayi Farida

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Ayi Farida

Ayi Farida has been working with the HIV/AIDS community in Indonesia for the last eight years, most recently with Médecins Sans Frontières as a treatment adherence counselor in Merauke, Papua. There, Ayi supervises local HIV/AIDS counselors in the district hospital. Over the course of her career, she has provided counseling, education, outreach, training, support services, and treatment access information to people with HIV/AIDS. She is a member of TREAT Asia's Asian Community for AIDS Treatment and Advocacy (ACATA).

TREAT Asia Report: Papua has only one percent of Indonesia's population but one-third of the country's reported cases of HIV/AIDS. Can you give us an overview of life in Papua and the nature of the epidemic there?

Ayi Farida: Papua is the easternmost province of Indonesia and it's more than three times larger than Java and Bali combined. It mainly consists of impenetrable jungle with enormous natural resources. One thing that makes Papua different from other parts of Indonesia is its great distance from the main island—it's approximately a 12-hour flight from Jakarta. While there are other remote areas of Indonesia, here the modern world is far away. Some villagers don't even live on the ground but up in trees.

AIDS cases in Papua are mostly transmitted sexually. Long ago, outsiders who wanted to take advantage of Papua's natural riches realized that its people were uneducated so they brought alcohol and women from Java and bartered them for local wood or other assets. So prostitution and alcohol became a part of Papuan life. In other parts of Indonesia, injection drug use is the main way HIV/AIDS spreads, but injection drug use scarcely exists in Papua. On the other hand, it wouldn't be surprising here to find sex workers in the middle of the jungle.

TA Report: What factors have made Papua so vulnerable to HIV/AIDS?

Ayi: The growth of Papua has been very slow in every respect—health care, economy, education. Poverty is a big issue. And poor education or even a total lack of education mean that people can't access the HIV/AIDS educational materials that are used in other parts of Indonesia. Leaflets, booklets, posters, and even movies cannot be used in Papua because many people cannot read or the language used is too complicated. And these materials deal mainly with drug use, which isn't so much of a problem in Papua.

Drinking and prostitution also create a problem. At some traditional parties, people get drunk and sleep with someone they just met and completely forget about condoms. A few tribes sometimes encourage exchanging wives. Magical beliefs also come into play. Some of the tribes believe that after they kill someone they have to have sex to cleanse themselves. In one of the tribes, it's impossible to campaign for condom use because their traditional beliefs say that sperm is something sacred that cannot be wasted or thrown away in a condom but should be deposited in the woman's vagina. These kinds of beliefs are very sensitive to discuss because they are seen as sacred.

TA Report: Can you tell us about your work in Papua?

Ayi: I'm working with Médecins Sans Frontières [MSF] mostly on treatment issues among people living with HIV/AIDS and their families. This also includes treatment education and some informational work with the general population. Most of our clients come to the clinic in town because if we visit them in their homes we might risk disclosing their status. Since we're based in a small town with very few outsiders, those of us who come from off the island are quite well known—almost everyone knows who we are and what we do. So, often it's impossible to do a home visit using an MSF car because people will suspect there is someone HIV positive in the house. Many times we have to disguise ourselves with a jacket and sunglasses.

People who live outside of town have to come in for ARV treatment because it is only available here, but to reach us can take them three hours by motorbike and then half an hour across the river by small boat and then continuing by rental motorbike or car.

My base is in Merauke town, which is the easternmost town in Indonesia on the border with Papua New Guinea. Even though Merauke is called a town, actually it's a remote and rural area compared with other towns in Indonesia. Sometimes you can't find any milk or even Coca-Cola. Fortunately I can survive with books, books, and books. My first week here was really hard—everywhere people looked at me as if I was a freak because they thought I was a foreigner. I did not feel comfortable until I was told that it was because I was a stranger to them. But I really do enjoy my life here. Wild nature, clean and fresh air, gorgeous beach!

TA Report: What are the main issues you face working on the front lines in Papua?

Ayi: Treatment education—I wish I could tell you how hard it is! It's such a great challenge to explain CD4 counts, the immune system, opportunistic infections, compliance, and drug resistance to people who don't read, don't watch TV, and have never had access to any kind of information. And it's all mixed with strong traditional beliefs. Wrong information and myths spread widely. People believe that a healthy looking person cannot have HIV/AIDS because someone with HIV/AIDS should look

skinny with a skin rash. When people get tested and the result is positive, they refuse to believe their status, they refuse to come to the clinic, and they refuse to use condoms. This is not two or three cases but many, many cases and they caused me great frustration when I first arrived here. Now we're trying to involve peer counselors to handle these cases.

Many Papuans believe in traditional or spiritual treatments rather than drugs. There's a famous fruit called red fruit that some claim can cure AIDS, and a spiritual treatment called light treatment that's supposed to help. Some believe paying money for religious activities can cure their illness, some are asked by traditional healers to fast, some are asked to take a shower in the middle of the night and pray to the spirit. In general people will try traditional or alternative treatments first, and after they fail they want to come to the clinic for the drugs. We have an ARV support meeting that is attended by people with AIDS under treatment and others who are candidates for ARVs in the next month. We hope that the ARV candidates can learn from the others at this meeting.

TA Report: In a remote rural setting such as Papua, how difficult a challenge is compliance with prescribed drug regimens?

Ayi: The Papuan way of life can present problems with compliance. Some people are too poor to have a clock, so it's impossible for them to take drugs exactly every 12 hours, at 8 a.m. and 8 p.m. Some Papuans survive as hunters, which means that they leave very early in the morning and spend a few days in the forest without knowing the time except sunrise and sunset. It's almost impossible to take drugs at the same time every day. Giving someone a watch isn't really a solution when they have never used one or paid attention to hours.

The other thing that creates poor compliance is related to the idea itself of taking drugs. Some people assume that drugs means cure, and it's very difficult to make them understand that ARVs do not cure AIDS. Last year MSF launched a campaign saying that AIDS could be treated. We got huge criticism from everywhere, NGOs and government, because they thought people might interpret the campaign incorrectly—if people know there are drugs, maybe they won't be afraid of the disease and they will stop using condoms. So MSF conducted a survey to see how the community responded to it and apparently yes, they did misinterpret it. They thought treated equals cured! So we haven't found the best strategy to tell the community that although there are ARVs, they're not a cure but they will improve your condition, so don't be afraid that AIDS equals death. Go get tested and seek treatment.

TA Report: Which groups do you work with most closely in Papua and what sort of prevention messages seem most effective with them?

Ayi: In Merauke my work is mainly on treatment issues, directly with patients. Prevention efforts here are aimed primarily at the clients of sex workers. MSF is trying a new campaign to convince them to use condoms because they have the power to decide whether to use them or not. They don't want to use them if they see a sex worker looks healthy. The message we try to emphasize here is that you cannot tell HIV-positive people by their looks, so use condoms.

TA Report: Does the Indonesian government provide support for isolated areas such as Papua when it comes to fighting AIDS?

Ayi: Since the central government recently embraced a decentralized system and granted special autonomy to Papua, the province is quite independent. Generally, the provincial government plays the main role in combating AIDS. It devotes quite a lot of its budget to fighting the epidemic. (AIDS here is bigger than among the other provinces.) Papua is the first Indonesian province to adopt policies 100 percent in support of condom use, while in other parts of Indonesia condoms are still a controversial issue.

The central government does give technical assistance and it supplies a lot of ARV drugs. People with HIV/AIDS can access free ARVs in Indonesia, although the regimens are still very limited and they haven't been proven safe and effective yet. But for Papuans the problem does not stop here. It's no use that ARVs are free if people don't want to use them because they don't believe in modern drugs.

Even if people believe in modern medicines, they still have to go to great lengths to get the drugs since it's government policy to distribute the drugs only in the district hospitals. Maybe we should change this policy for Papua because many places are far from the hospital or the nearest health-care facility equipped to treat severe side effects or even opportunistic infections.

But the greatest problem is trained doctors and nurses. ARVs can be accessed easily but there are not so many doctors trained to use them. They don't know how to prescribe, what should be done in case of side effects, and so on.

TA Report: What are the community's attitudes toward people with HIV/AIDS?

Ayi: Stigma and discrimination are commonplace here.

In the villages there's a tradition that when people get a severe illness they are separated from their families and isolated. This kind of thing has happened to some patients at an MSF clinic. Sometimes they just lock the sick in a room, never clean it until the room is full of urine and feces, and place the food on the floor until the person finally dies. Or, even worse, they bring the sick to the forest and burn them alive to cleanse the village and the family because they believe it's a curse.

TA Report: Can you tell us how you became involved in working against HIV/AIDS?

Ayi: I've been working on this issue for eight years. I grew up as a city girl in Jakarta 26 years ago. I moved to Jogjakarta, Central Java, to continue my studies, and there I discovered my interest in social work. I started working as a literacy teacher with an HIV/AIDS NGO and as an outreach worker with female sex workers in Jogjakarta. Later on I jumped into the prevention field, working with various groups such as gays, transvestites, youth, street children, prisoners, migrant workers, and also with religious leaders and the provincial government.

Four years ago I moved into the care and treatment field because at that time many people couldn't access treatment and medicines were far from affordable. I worked with the Jogjakarta Network of People Living with HIV/AIDS, encouraging and assisting them to establish an NGO of their own, and I acted as the program

manager.

After Jogjakarta I moved to Jakarta with MSF's Access to Essential Medicines campaign, working on accessibility and quality assurance of ARV drugs in Indonesia. Since I'm also a psychologist, MSF sent me for a short time to Aceh for a mental health program, but since my heart was already in HIV/AIDS I proposed being sent to Merauke as a treatment adherence counselor. And here I am.

TA Report: You've been fighting AIDS at a community level for a long time. What are your greatest frustrations and your greatest satisfactions?

Ayi: My greatest frustration is when I lose my patients because of discrimination by health-care staff. Recently one of the patients died tragically because the doctor refused to do a C-section when she had been in labor for almost 72 hours. She was being treated to prevent mother-to-child transmission and she was very good, but finally the baby died inside and the doctor still refused to take any action until she also died. We had followed her from the beginning with counseling and medicine.

This is not the first case of discrimination from health-care professionals. I don't know why—they have enough information but still they discriminate. Earlier, one of my favorite patients died because no hospital wanted to take care of her when they knew her status. When that happens it feels useless that I'm working hard on this issue. But when I see the other patients smiling, when I watch their progress and see what they've been able to do because of my assistance...and especially when I see the children—their eyes, their smiles, encourage me to fight for their future and combat this epidemic.

Source: TREAT ASIA (<http://www.amfar.org/cgi-bin/iowa/asia/index.html>)