# Oh, Suzana!

In Indonesia, PWAs shroud themselves in lies, secrets and silence. But designer-activist Suzana Murni, 28, has rent the veil of shame. Murni's mantra? It's not the label -- it's how you wear it.

July 1, 2000 By Angelo Ragaza

---

In Indonesia, we value politeness at all times. We respect our elders, cherish our relatives and are close to our neighbors. But when you catch HIV, all these good qualities can boomerang for you, your family, your village. It's all about shame.

Shame that you don't take care of your children, so they catch HIV. Shame that your wife is a bad woman who plays around while you're away. Shame that your son is gay, that you have a promiscuous employee or neighbor. Shame makes it easy to save face by blaming those who are weaker. Shame has influenced our HIV prevention materials -- as a result, people miss the message or turn their back on condoms or clean needles. An official in the district I live in once refused to conduct an AIDS education class because "I don't want people to get the wrong idea about our district -- that we have sex workers here." Shame is the source of the terrible silence of AIDS throughout Asia.

**INDONESIA**

**Total population**
203,480,000

**Number of people with HIV**
**UNAIDS** 51,960
**Official gov't** NA

**Number of people with AIDS**
**UNAIDS** 4,800
**Official gov't** 153

**Number of openly positive** 5

**Transmission Mode**
24% **Homo**
72% **Hetero**
3% **IDU**
1% **Blood products**
New democratic reforms spell hope for PWAs, while health care remains poor and TB high, HIV infections remain low. But the IDU population is 2 million and counting, and half have HIV.

I was diagnosed here in Jakarta in 1995, around the same time that my partner died. My family did not know much about AIDS. So when the doctor said to wrap his body with a plastic sheet, we did. But when we were told to burn his clothes and shoes, I felt awful. I buried them in the ground instead.

I was very lonely and isolated. I thought, “OK, I’ll just wait to die.” I stopped working -- I’d been a clothing designer. I didn’t do anything. After six months, I didn’t get sick, and I was pretty pissed off. I also realized that there must be many things about HIV that I didn’t know. There was information about prevention and condoms and even clean needles, but nothing about care and treatment for people who already have the virus. Five years ago, all we heard was that people who were infected died quickly. We were groping in the dark and believing in the gossip and myths of the media.

That’s when I started searching for information and other HIV-positive people. I had a very good doctor, through whom I made contact with others who have the virus -- a mother, two gay guys, a straight man. At first, we all felt very relieved. If we worked together, we could break the feeling of isolation. We had fun -- the first I’d had in several months. This became the first peer support group for HIV-positive people in Indonesia, called Spiritia, from the word spirit. In the absence of treatment, spirit is what you need to go on.

In 1995, information about support, care or positive living was almost nonexistent. I was very lucky that I could speak English. When I was in ninth grade, I was a high school exchange student in a small town in Louisiana -- Lake Charles -- and later on went to art school in the United States. That’s where I got my first HIV brochures and books, which I later translated and distributed in Indonesia. Those brochures and books are also where I learned that an HIV-positive person can get a dignified burial -- just like anybody else. I felt guilty and angry about what had happened to my partner, but it wasn’t my fault -- I didn’t know better. Still, I felt I hadn’t done enough for him.

That anger has been the motivation that drives me. I want to see big changes happen while I’m still around. That’s why I got involved. At the moment, I’m Spiritia’s director. I am also a founding member of the National Coordinating Group of the International AIDS Candlelight Memorial, formed in 1996. I chair the Indonesian Communication Forum of NGOs [nongovernmental organizations] Working in HIV/AIDS, which I represent on the National AIDS Commission. And since 1995, I’ve represented Indonesia for the Asia Pacific Network of People Living with HIV/AIDS (APN+), helping document human rights violations and violence against people with HIV. And I’m also still designing clothes. I have a couple of women who do the embroidery for me.

I do not take any antiretrovirals -- they’re too expensive. A regimen would cost $2,000 a month, and the average Indonesian makes maybe one-fourth of that. Economically, in Indonesia, I fall in the middle. After the Asian economic crisis of 1997, there were more low-income people than ever. The few Indonesians who are very rich can travel to Australia every three months for checkups and medication. I can sell my car for a six-month supply -- then what? So I just take it easy. I learn to understand my body and other options to stay healthy. I enjoy my life and strive to make it better without forcing myself. My family -- my parents and my husband, Sahrul -- are my major source of

strength. My brother and sister are also very cool and sometimes volunteer for my organization.

The situation for people with AIDS in Indonesia has improved over the past five years but discrimination remains -- as it does throughout Asia.

Even if a country endorses the proper ethical principles recognized all over the world -- voluntary, anonymous testing, confidentiality and counseling -- it doesn't implement them. National HIV surveillance is supposed to be anonymous, but blood samples are labeled with names. People still get tested without their consent -- poor patients in hospitals, for example, job applicants having medical checkups, many people -- and after the result comes, there is no counseling, and their confidentiality is breached, causing a shock, more stress and loss of hope right from the very first moment of living with HIV. And there have been plenty of cases of people testing positive and then losing their jobs or sex workers being put out in the streets.

AIDS programs in Indonesia, whether run by the government or NGOs, have always focused on general prevention. Treatment, care and support of HIVers have all been left in the hands of those whose lives are directly affected, including doctors who have patients with HIV. NGOs in provinces with high prevalence have begun creating their own support programs, but most are still reactive and unprepared for the growing number testing positive. Even in the past few months, the number of IV-drug users who have found out they have HIV has increased exponentially. After all this time, people -- in government, NGOs, health care facilities, schools and families -- are finally realizing that HIV is all around them.

It can be empowering for HIVers to speak out here, just as it is in the West, but it is also terrifying. People in Asia literally risk their lives to come out -- even people who are just *suspected* of having HIV are in danger. Recently a person in India was set on fire. Here in Indonesia one was attacked by a mob. There are many, many horrible stories.

If coming out doesn't kill you directly, it can kill you slowly. You may lose your livelihood, so you can't afford to feed yourself adequately, let alone pay for drugs. You can lose your house. I know a positive couple who live like nomads because nobody will rent to them. Speaking out in public can also rob you of your dignity, because people will judge you harshly, turning you into a bad example. If you speak out about how badly you've been treated in a hospital or by your community, the authorities can easily silence you.

As I've said, it's all about shame. But we can't afford to say, "We are good people and they are bad people" anymore. I think Indonesia is now starting to wake up.

---

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/Oh-Suzana-1376-8406