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"Without international aid, Indonesia could not provide necessary drug supply".

Interview with Ani Herna Sari from Indonesia, in preparation for our conference "Global Health Champion Germany? From HIV to SARS-CoV-2. What have we (not) learned?"

Text: Axel Schock. Photo: Ani Herna Sari

The Covid 19 pandemic has also made the treatment and care of people infected with tuberculosis in Indonesia so much more difficult that growing infection and mortality rates are to be expected again. The self-help organisation Perkumpulan Rekat Surabaya, in which Ani Herna Sari is active, has nevertheless found ways to support sick people despite the adversities.



Photo: Ani Herna Sari, Indonesia

A phase of discrimination began

These were probably the two most terrible years that Ani Herna Sari had to endure. After she was initially misdiagnosed with tuberculosis in 2011, the misdiagnosis led to a multi-resistant form of the disease. To make matters worse, the therapy coincided with her pregnancy. The physical strain was enormous, the daily injections often associated with great pain, and this was perhaps also the reason why she went into labour a month early. But with the delivery, as Ani Herna Sari tells us, "a phase of discrimination began, the likes of which I could never have imagined". At the hospital, she was kept isolated in a room that could be seen from all sides. "There was no privacy at all. It was just

shameful." The fact that her months of therapy had been successful and that her tuberculosis tests had already come back negative was simply ignored, says the communication scientist, who lives in Surabaya on the Indonesian main island of Java.

Traumatic experiences in the maternity ward

Her child was also kept separate. Because the nurses wanted to avoid any touching, the newborn was not given a bottle, but only pressed close to her head.

When the baby was discharged from the hospital eight days later, the consequences of this brutal and insensitive treatment became apparent: the top of her skull was flattened by the milk bottle on one side of her head.

The experience was traumatic for Ani Herna Sari. "They were certainly special experiences I went through as a pregnant woman with tuberculosis, but it is still important for me to talk about it," she explains. "I don't want anything similar to happen to any mother or child." And she does not only want to point out the abuses, but also to campaign for more support and investment in the fight against tuberculosis and especially in the Global Fund to Fight AIDS, Tuberculosis and Malaria. It is thanks to this fund that she survived the disease.

Ani Herna Sari, who is currently doing her doctorate at the University of Airlangga, first joined Perkumpulan Rekat Surabaya, a self-help organisation that helps people suffering from multidrug-resistant tuberculosis to successfully complete treatment. A small team educates people about the disease and treatment and helps them to get treatment. Clients who are unable to attend clinics due to physical limitations are provided with the necessary medication.

Peer-to-peer help for others affected by the disease

In 2021, Ani Herna Sari became Vice Chairperson of Perhimpunan Organisasi Passion TB Indonesia, a national network of survivor organisations. In the meantime, her commitment also extends beyond the country's borders. For example, she also works for the newly founded organisation TB Women Global, a network of women whose agenda includes the promotion of gender equality and human rights in TB control.

The various fields in which Ani Herna Sari is involved in Indonesia for the rights and treatment of people with tuberculosis and HIV alone show how numerous and complex the obstacles and challenges that need to be overcome still are.

"There are still many people with tuberculosis or with HIV who are not on treatment. And without international aid, Indonesia would not be able to manage the supply of drugs to those infected," says Ani Herna Sari.

The number of tuberculosis deaths is increasing worldwide

According to the World Health Organisation's Global Tuberculosis Report 2019, Indonesia ranks third in the world with 845,000 tuberculosis cases per year. This includes 21,000 HIV-tuberculosis co-infections and about 24,000 multidrug-resistant tuberculosis cases that are particularly difficult to treat. Of the more than 10,000 patients with known HIV status, only 4,000 had received antiretroviral therapy in 2019.

The Global Fund not only finances drugs for tuberculosis treatment until a complete cure is achieved, but also regular sputum and blood tests. The Global Fund also provides support so that people can return to work after years of treatment. For Ani Herna Sari, it is also very important that the Global

Fund builds capacity in the communities, strengthens advocacy and implements practical prevention programmes.

"Tuberculosis mainly affects people in the lower income classes. They are effectively without income due to the disease," explains Hernasiri. The Global Fund therefore also supports those in need directly with cash payments - for example, to cover the travel costs for regular visits to the clinic.

A fundamental problem, however, is still contact tracing.

"Many infected people are ashamed when they receive their HIV or tuberculosis diagnosis," Ani Herna Sari tells us. Stigmatisation and discrimination are still very high in Indonesia. Many therefore move to another district - and are then no longer accessible for health facilities or self-help organisations. There is also the danger that they will pass on the infection.

There are also still regions where people are very sceptical about the therapies and prefer to rely on traditional medicine. "We still have a lot of work ahead of us to educate people about the diseases, the ways they are transmitted and the possibilities for curing them," says Ani Herna Sari.



Photo: Ani Herna Sari, Indonesia

The Corona pandemic worsened the situation

Covid-19 has made an already difficult situation even more difficult, and drastically so.

In Indonesia, too, the Corona pandemic shut down social life, imposed contact restrictions. And for Ani Herna Sari, new tasks were added. Her organisation, Rekat Surabaya, works closely with the Surabaya administration's health department to monitor and assess the COVID-19 situation in the province - and to inform the health department about the situation of those suffering from

tuberculosis. Through the organisation's social media platforms, Rekat Surabaya disseminates targeted information on COVID-19 prevention and safety measures for people affected by tuberculosis.

However, the measures to contain the COVID-19 pandemic also meant the loss of their jobs for many. However, there is no government support in such cases. The affected people therefore had to leave the cities and return to their home villages. There, however, their therapies are not continued. The impact of the pandemic on tuberculosis treatment is immense, worldwide. Two-thirds of all tuberculosis programmes have been interrupted, and laboratory diagnostic capacity has been used in many places for covid-19 instead of tuberculosis.



Photo: Ani Herna Sari, Indonesia

The World Health Organisation expects that the number of people dying from tuberculosis will also increase. Half a million people alone, it is estimated, will have died of tuberculosis in 2020 because they were not diagnosed.

However, these figures will only be reflected in the statistics to a limited extent, because in the pandemic the reporting system also collapsed in many countries.

And worldwide, about 1.4 million fewer people were treated for tuberculosis than in the previous year. The biggest drop, by 42 %, was in Indonesia.

Organisations like Rekat Surabaya have nevertheless found ways to ensure that the therapies can be continued as seamlessly as possible even under these difficult conditions.

Tuberculosis patients in Indonesia have to come to their clinic every day to take their medication. This is to ensure that the therapy is not interrupted. The side effects are sometimes very severe, explains Ani Herna Sari. The patients sometimes feel so sick that they cannot work and therefore avoid taking the medication. But due to the Corona pandemic, public transport was temporarily suspended, so clinic visits had to be organised with private vehicles. When weekly take-home delivery became possible, the Rekat Surabaya team delivered the tuberculosis drugs directly to the clients' homes. The clients were reminded daily with a WhatsApp video call and at the same time it was ensured that the medication intake was continued regularly and properly.

According to Ani Herna Sari, the Corona crisis has once again Photo: Ani Herna Sari, Indonesia

shown that diseases have different connotations in society.

Tuberculosis, stigma and self-stigma

"Covid-19 sufferers can be sure of support. The state provides treatment and, if necessary, food," says Ani Herna Sari. Tuberculosis sufferers, on the other hand, are shunned for fear of infection. "This leads to de facto social isolation. My best friend is gay and HIV-infected, but he has not dared to tell his partner until today - out of shame - and I have to assume that he is also infected. The fear of stigmatisation makes talking about the infection impossible for many, even within a relationship.

"I completely withdrew from social life during the stages of the disease and ended up stigmatising myself," Ani Herna Sari openly admits. "I didn't want to infect anyone, of course. Fortunately, my family and also some friends were very supportive."

Although there are government programmes to reduce stigma and discrimination against HIV and tuberculosis patients, which also involve representatives of key groups, the community and religious communities, she believes that community-based programmes are just as important. However, in their opinion, community projects by and for people infected with HIV and tuberculosis are just as important.

In the tuberculosis groups, for example, other people with the disease and those who have recovered share their experiences, but also give each other tips on how to support recovery, for example through activities such as morning walks. "But the exchange is also important for the spiritual well-being, for example to encourage each other to get through the not always easy therapy to the end."

I could not decide in which country I would be born

But without international help, these infrastructures cannot be further developed and maintained. Ani Herna Sari hopes that the richer countries of the world community, such as Germany, will provide the Global Fund with sufficient resources.

"I could not decide in which country I would be born and whether I would grow up in a rich or poor family," says Ani Herna Sari. "But I strongly believe that everyone has the right to be protected from diseases and to be able to breathe. That's why I hope we continue to get the support to be able to fight HIV, malaria and tuberculosis in Indonesia and elsewhere."

Thanks to Axel Schock for the article and to Ani Herna Sari for sharing her story and to the Global Funds Advocates Network for facilitating!

[To register: Register for the conference "Global Health Champion Germany?! From HIV to SARS-CoV-2 - What have we \(not\) learned?" here](#)

Further information:

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