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World Tuberculosis Day 2017: Govt rollout of TB drug slow, say experts

Bedaquiline may be the answer to several drug resistant patients in India, but the government is extra cautious about the rollout.

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Written by **Tabassum Barnagarwala** | Mumbai | Updated: March 24, 2017 1:09 pm

Shahida Bano was lucky, doctors believe. On November 4, 2016, multiple tests confirmed she had multi-drug resistant (MDR) tuberculosis. Within three months, on February 7, the young mother, a Mumbai slum-dweller, was part of a national clinical trial for Bedaquiline, the first effective drug for TB to have made an appearance in 50 years.

At 22, Shahida is frail and shivers often, but can feel the drug improve her strength everyday. "I weigh 44 kg. The joint pain never goes. When drugs had no effect, the doctor asked if I want to try Bedaquiline. They say it can cause heart problems, but I will try anything," she says. Admitted at Sewri TB Hospital, she hopes to return, cured, to her Wadala shanty. Her husband, a driver, and their one-year-old son have been kept at a distance due to the risk of infection.

Bedaquiline may be the answer to several drug resistant patients in India, but the government is extra cautious about the rollout. The drug has been approved for only 600 patients for a six-month regime. Shahida is one among over 200 patients selected so far including 68 in Mumbai.

But not every drug resistant TB patient is as lucky as Shahida.

A 22-year-old Ghatkopar resident, Pooja Patel, required this sought-after drug, having visited private doctors for years before approaching Medecins Sans Frontieres (MSF) in 2016 with severe malnourishment and damaged lungs. Her only hope was a new drug such as Bedaquiline. "But it was too late. She passed away last November, before we could procure it," says Dr Pramila Singh, MSF clinic coordinator.

Experts say that like Singh, 30 per cent (over 43,000) of India's drug resistant TB population may be in need of Bedaquiline. The Revised National Tuberculosis Control Programme (RNTCP) recently requested the government to fund Bedaquiline for 10,000 patients, but activists say the talks led nowhere. A Lancet report claims 1.9 lakh drug resistant patients die annually — the largest numbers are in India, along with Russia and South Africa.

"The rollout in India is glacially slow. How sad is it that patients have to access the court to get the drug," says chest physician Zarir Udwadia, who has treated 30 patients with Bedaquiline since 2014 and found a 70 per cent success.

A Thane girl, aged 20, now suffers from extremely resistant TB. In years of treatment, she has consumed about 10,000 pills and hundreds of injections, to no avail. Recently, she was referred to Mumbai's RNTCP for Bedaquiline enrollment. While she is eligible, there is no trained physician to monitor her if she is put on the regime.

"She may have to shift to Mumbai for treatment. There are several patients like her who live in rural regions where there is no training on Bedaquiline," a government official said.

According to Erica Lessem, activist with the US-based Treatment Action Group, by restricting access to Bedaquiline, "the government is practically guaranteeing the development and spread of TB".

(Names of all patients have been changed on request)

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