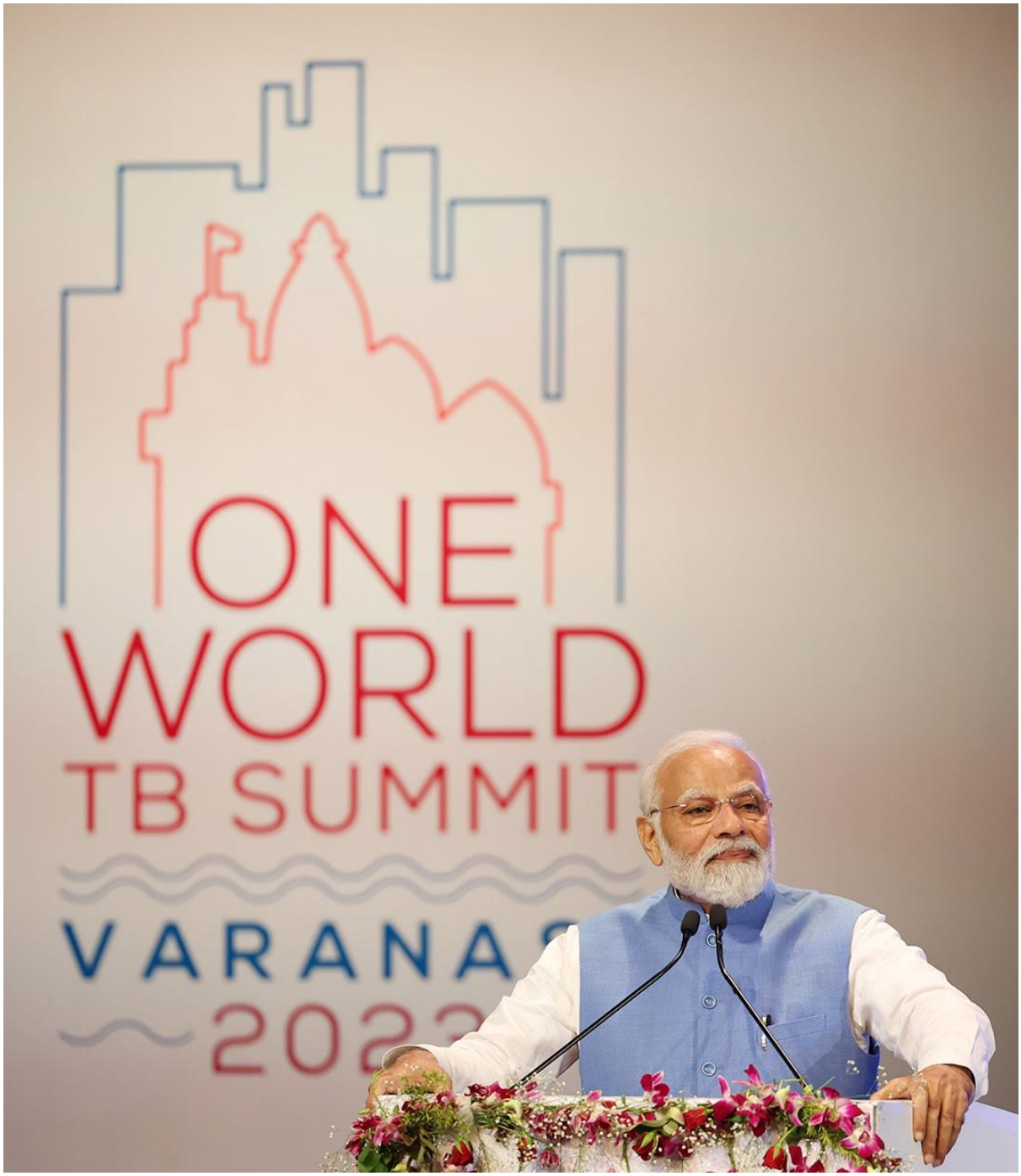
THE CARAVAN
A journal of politics & culture

The CARAVAN, August 2024

Death by Policy

The Modi government's catastrophic failure to control tuberculosis



Addressing the One World TB Summit in Varanasi, Narendra Modi boasted that “India’s efforts are a new model for the global war on tuberculosis.” PRESS INFORMATION BUREAU

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01 August, 2024

ON 24 MARCH 2023, commemorated by the World Health Organization as World Tuberculosis Day, Prime Minister Narendra Modi inaugurated the One World TB Summit in his Lok Sabha constituency of Varanasi. With characteristic and unearned confidence, Modi reiterated his promise, first articulated five years earlier, to eradicate the disease in the country by 2025. As part of his claims to world leadership during India’s presidency of the G20, he boasted that “India’s efforts are a new model for the global war on tuberculosis.”

The doctors and patients actually waging the war had a damning assessment of this “new model.” In 2023 alone, over three hundred and twenty thousand Indians died of tuberculosis—a curable and preventable disease—accounting for over a quarter of the global mortality figures. Today, thanks to rampant misgovernance, India’s 2.8 million tuberculosis patients struggle to access the drugs that would save their lives. “It is like we have learnt nothing from COVID-19,” Ganesh Acharya, a tuberculosis survivor and activist, told me. “We are in a public-health emergency of genocidal proportions. It sounds like an exaggeration, until you look at the number of people dying.” Two separate epidemiologists used a different term: policide, or death by policy.

A hallmark of India’s failure to control tuberculosis—one that should define the Modi years, much like Thabo Mbeki’s government in South Africa is remembered for its AIDS denialism in the early 2000s—is that politics has trumped science, as well as humanity, every step of the way. The Modi government’s flagship tuberculosis control policy, the Pradhan Mantri TB Mukt Bharat Abhiyaan, creates a medical dystopia in which corporations, non-profits and individuals are invited to “adopt” patients. By pledging support for up to three years, the donors, known as Ni-kshay Mitras, can get themselves photographed handing food baskets to patients. “TB has so much stigma, and the government is using patients as props for photo-ops,” Acharya said. “It is so humiliating.”

President Draupadi Murmu launched the scheme, in September 2022, by noting that, “in some patients or communities, there is an inferiority complex associated with this disease, and they view the disease as a stigma.” Murmu was, in essence, placing the blame for the stigma on the stigmatised. “Everything has become a photo-op for some director of some company, without any care for how patients are being robbed of their dignity,” a tuberculosis researcher told me, on condition of anonymity. “This is an infectious disease. Confidentiality has to be maintained. Historically, Indian governments have implemented food delivery schemes without this tacky photo app.” According to a government dashboard, over a hundred and sixty thousand Ni-kshay Mitras have committed to supporting nearly a million patients by providing food baskets worth Rs 700 per month. Almost eighty percent of the donors have signed up for just six months.

“TB has so much stigma, and the government is using patients as props for photo-ops,” Ganesh Acharya said. “It is so humiliating.”

Even as it abdicates its responsibility to provide nutritional support to tuberculosis patients, the government has also failed to provide them adequate healthcare. Despite Modi’s rhetoric, patients are staring at a cataclysmic tragedy: older drugs are out of stock, while newer therapies are not being approved.

Over the course of Modi’s second term as prime minister, there were three major pan-India stockouts of tuberculosis medicines. In April this year, with the campaign for the general election in full swing, Maharashtra, the hottest of the world’s tuberculosis hotspots, had only fifteen days’ worth of medicines left. By July, Blessina Kumar, the CEO of the Global Coalition of TB advocates, told me, the Champaran region of Bihar had completely run out. Doctors were left with the impossible task of rationing drugs among patients, who were, in turn, skipping doses to make their precious allotments last longer. When patients miss doses, it boosts antibiotic resistance in the community, turning a treatable disease into a nastier, drug-resistant version. India has the world’s highest burden of people with drug-resistant tuberculosis: nearly a hundred and twenty thousand, as of 2021.

Tuberculosis was made even more deadly by the lockdowns and treatment disruptions during the COVID-19 pandemic. Plagues are, after all, shaped by other plagues. The pandemic demonstrated the Modi government’s disdain for science and its insistence on treating infectious diseases as an

issue of law and order, rather than public health. It also showed that our health policy has global implications. When India stopped exporting vaccines during the deadly second wave, it had a domino effect on the pandemic response in over ninety nations.

With the situation deteriorating in the ensuing years, we are in a health crisis of epic proportions that has not reached—and, perhaps, will never reach—the swanky television studios of Delhi, which continue to play up imagined threats while ignoring the deadly pathogens lurking among us. Meanwhile, India's army of malnourished tuberculosis patients are doing the only thing that desperate people pushed to the very brink of existence can do: leaving their stories behind.

The former health minister Mansukh Mandaviya hands over a food packet to a tuberculosis patient under the government's Ni-kshay Mitra scheme. The initiative has been criticised for compromising patients' privacy and robbing them of their dignity. PRESS INFORMATION BUREAU

THE MODI GOVERNMENT'S "POLICIDE" has jeopardised global efforts to eradicate tuberculosis, which, according to the United Nations' sustainable development goals, has a deadline of 2030. Research published in *The Lancet* noted that, while the WHO's "End TB" strategy aims for a ninety-percent reduction in the incidence rate of tuberculosis between 2015 and 2030, the rate in India fell by only 0.5 percent in the first five years of that period. The lack of progress has also brought the country's response to HIV, which was already tottering, to its knees.

Tuberculosis and HIV—two of the deadliest killers known to humanity, having killed more people than the two World Wars put together—are an efficient tag team. At the height of the AIDS epidemic during the 1990s, they came to be known as the "cursed duet," as patients with HIV began dying of

tuberculosis. If you are infected by HIV, you do not die of HIV. By switching off the body's immune system, the virus creates an opportunity for other diseases to plunder the body through "opportunistic infections." Tuberculosis is the leading opportunistic infection among HIV patients. People living with HIV are around twenty times as likely as others to contract tuberculosis.

Both HIV and *Mycobacterium tuberculosis* are master mutators. They have lengthy periods of latency, during which they lie low and wait for immunity to be depleted. Neither pathogen kills its host immediately, which is a huge evolutionary advantage that allows the disease to spread. This makes disease surveillance, forecasting patients' medical needs and establishing trust among the community critical.

In 2022, the HIV-positive community faced stockouts similar to the ones tuberculosis patients are currently experiencing, with at least half a million people reportedly struggling to access antiretroviral drugs. Patients protested for over three weeks in front of the health ministry, which denied the shortage. Sujatha Rao, a former health secretary who set up India's HIV programme during the 1990s, told me that the stockouts took place because "the government messed up the procurement cycle." Rao recalled being told that a bureaucrat in the ministry "sat over" the tendering process, causing delays. "It is important to do the boring stuff well, like inventory and forecasting," she said. "I used to constantly monitor it and maintain a three-month stock. These are not paracetamol tablets that you can buy in a pinch from the market when you run out."

Rao added that the tuberculosis stockouts had similar causes. "TB patients are so upset," she said. "During COVID, the government diverted every resource from TB, and we are now seeing the impact. These disruptions are not acceptable at all. I am sad every time I look at India's disease burden data—so much malnourishment—all of it is interlinked."

The HIV programme was one of India's more successful public-health interventions, halting the progress of an epidemic that was devastating the developing world. The secret to the success was prevention. Advertisements promoting safe sex were common on television, celebrities such as Shabana Azmi attempted to destigmatise the infection and sex workers collaborated with the health ministry to advocate for condom use.

Since Modi came to power, the entire approach to infectious diseases has radically changed. In June 2014, the health minister at the time, Harsh Vardhan, controversially argued that fidelity in marriage was more important than condom use in preventing AIDS and proposed a ban on sex education in schools. "There is a conservative attitude, and the systems that were laid down are not being used," Rao said. "Advertisements promoting condom use, safe sex, et cetera, have completely disappeared from public discourse. Everything is about Ayushman Bharat and insurance coverage. Insuring people is not adequate for public health." Around 2.4 million Indians now live with HIV. In 2022, there were around sixty thousand new cases and over forty thousand deaths—most of them from tuberculosis.

In August 2022, after stockouts left over half a million people with HIV struggling to access antiretroviral drugs, patients and activists protested for over three weeks in Delhi. The health ministry simply denied the shortage. ALTAF QADRI / AP PHOTO

“WE’VE RUN OUT OF MEDICINES, let resistance develop and allowed this disease to spiral out of control,” a Delhi-based activist told me, on the condition of anonymity. “Far from eliminating TB, we are now staring at a volcano of resistance.” This is the result of the “boring stuff” Rao was talking about: the procurement process. For a country as large as India, the union health ministry has to purchase tuberculosis drugs in bulk, which means that a supplier can corner the entire Indian market with a single government tender.

India’s last big order for anti-tuberculosis medicines, worth around Rs 800 crore, was issued by the Central Medical Services Society in 2020. The drugs were delivered in phases over the next year. By September 2023, supplies were expected to run out within the next six months, and the CMSS again floated a tender. This contract, worth Rs 600 crore, was won by two companies: J Duncan Healthcare, based in Maharashtra’s Thane district, and Centurion Laboratories, based in Vadodara, Gujarat. Both companies failed to deliver the drugs in time, resulting in the current crisis. I asked J Duncan and Centurion why they had not been able to fulfil their tenders but received no response.

The Modi government repeated the mistakes it had made during the COVID-19 pandemic, with state governments having to bid against each other for essential supplies.

“These companies had no history of supplying such large-scale tenders,” the activist said. Unlike the usual suppliers of tuberculosis drugs, such as Svizera Healthcare, Lupin and Macleods Pharmaceuticals, they did not have any capacity to produce active pharmaceutical ingredients—the raw material for the drugs—and were forced to rely on Chinese suppliers. However, in 2019, China passed environmental regulations that severely affected API exports, a fact that was well known by the time the tender was issued and should have been taken into account by the CMSS.

On 26 September, the union health ministry issued a press release, claiming that media reports about drug shortages were “false, misleading, motivated and seem deliberately intended to deceive and misguide people.” On 13 December, it doubled down, categorically stating in another press release, “There is no shortage of anti-tuberculosis drugs in the country.” However, state governments began reporting dwindling supplies in January and, by World Tuberculosis Day this year, many of them barely had enough drugs to last another month. A report in *Scroll* noted that doctors were asking patients to forego their usual cocktail of three or four drugs and take a single antibiotic, though this often necessitated having to take as many as nine doses a day, which affected patients’ ability to eat.

Having created a crisis, the Modi government repeated the mistakes it had made during the COVID-19 pandemic, when poor forecasting and dire urgency resulted in state governments having to bid against each other for essential supplies of protective equipment, diagnostic tools and, most memorably, medical oxygen. After J Duncan and Centurion failed, the union health ministry tossed the ball to state governments, on 18 March, asking them to purchase their own stocks for the next three months, while it issued an emergency tender and asked the WHO for help.

When a bulk procurer like the union government cannot ensure supplies, decentralising the process only makes things worse. State governments have limited budgets and lesser power to negotiate on quantity, price and delivery timelines. Moreover, Svizera, Lupin and Macleods were all contractually bound to honour existing export agreements, including to the WHO’s Global Drug Facility, which procures anti-tuberculosis drugs for the world.

On 27 March, Dinesh Gundu Rao, the health minister of Karnataka, wrote to his union counterpart, Mansukh Mandaviya, asking for additional funds to procure the drug. He noted that the model code of conduct for the upcoming general election was causing delays in the procurement process, as was the fact that companies would require time to manufacture the necessary amounts. “While I do not wish to accuse the Union government of callousness, I have to point out that State support for the TB patients has been jeopardised by this action of the Centre,” he wrote. “Both the delayed communication to procure a critical drug (whose procurement is problematic in the short run) and also issuing the communication during MCC have adversely affected the efforts of the State government in this regard. Under these circumstances, the Union government has an obligation to respond immediately and support the State to keep up the supply of critical drugs to the TB patients at a required level.”

Over the course of Modi's second term as prime minister, there were three major pan-India stockouts of tuberculosis medicines. NURPHOTO / GETTY IMAGES

"The TB policy is a complete mess," Yogesh Jain, a co-founder of the Jan Swasthya Sahyog, told me. "We are back to the situation in the '80s, before there was even a national TB programme and we would run out of medicines all the time—our patient outcomes were terrible." The state governments, he said, passed on the burden of procurement to district administrations. "At the district level, officials went scampering to pick up medicines in the open market. This is no way to procure medicines for a country the size of India. We have lost it."

While tuberculosis patients wait for medicines, HIV patients have to make do with drugs of questionable quality. "In this heat, the medicine melts," Manoj Pardeshi, an executive board member at the National Coalition of People Living with HIV in India, told me. "It is also bitter and powdery. Sometimes, the tablets are cracked when we open up the packaging. This batch turns into powder." Between 2004 and 2020, tenders floated by the National AIDS Control Organisation included a quality criterion, which was a mandatory requirement for policies that relied on external funding—in this case, from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Moreover, bidders had to manufacture at a site approved by the WHO. Both requirements were dropped, the Delhi-based activist told me, once India moved to exclusively domestic funding. They added that J Duncan and Centurion supply HIV drugs to the NACO as well. "Normally, they would be blacklisted, if you pick up a tender and fail to meet it, but there seem to be no consequences."

A FEW YEARS AGO, when things were nowhere as bad as now, Shreya Tripathi, a teenager from Patna, took the Modi government to court. Tripathi contracted tuberculosis in 2012, when she was 13 years old. She did not respond to treatment and was diagnosed as having extreme drug-resistant tuberculosis. In 2016, a Mumbai doctor prescribed bedaquiline, the first new tuberculosis medicine to be registered in almost fifty years. Four years earlier, the US Food and Drug Administration had given bedaquiline accelerated approval in order to make it available to patients who needed it.

However, India had not updated its drug protocol in line with WHO guidance on the drug, and the National Institute of Tuberculosis and Respiratory Diseases, in Delhi—one of six centres in the country authorised to administer bedaquiline at the time—refused to allow her to try it.

In January 2017, the Delhi High Court ordered that Tripathi be given access to the drug and that bedaquiline be made available in 70 centres around the country. But, by then, her lungs were already damaged beyond repair, and she died on 9 October 2018, at the age of 19. “Even if it’s too late for me, at least other patients will benefit from it,” she told *The Guardian*, days before the verdict. “Just imagine how hard it must be for really poor people to get this drug.”

The naïve among us thought that Tripathi had cleared the way for other patients with drug-resistant tuberculosis, but, today, they find themselves fighting the same battle all over again. This time, the fight is over BPaL, a 26-week regime of three drugs—bedaquiline, pretomanid and linezolid—that the WHO recommends as the treatment for drug-resistant tuberculosis. It has demonstrated a success rate of around ninety percent in clinical trials and is cheaper than the conventional treatment, which lasts almost two years and has a success rate of only sixty percent. BPaL is estimated to reduce annual treatment costs in India by $145 million, or over Rs 1,200 crore.

Pretomanid was developed by TB Alliance, a non-profit drug development organisation, which manufactures it in a Visakhapatnam factory and exports it to over seventy countries, where over forty thousand patients have benefited from BPaL. India, however, remains the exception, despite being the epicentre of drug-resistant tuberculosis. The Modi government approved BPaL, in 2020, only as part of a pilot programme. Doctors cannot prescribe it to patients, as the health ministry is yet to publish guidelines on its use. And so, a revolutionary and historic breakthrough for tuberculosis treatment is caught up in labyrinthine bureaucratic processes, even as patients struggle to access older drugs.

The guidelines are expected to be published next year—too late for the hundreds of thousands who have perished in the interim. A health ministry official involved with the pilot process told me, on condition of anonymity, that the guidelines would be approved “any day now.” When I mentioned this to a tuberculosis patient, they said, “We have been hearing this for the last one-and-a-half years.”

“To let people die when a medicine is available is unconscionable,” a researcher at an international NGO told me, on condition of anonymity. “I have talked to hundreds of people and I cannot understand what the reason for delay is. It has been recommended by the WHO and is being used in seventy countries. The drug has passed all checks and balances for safety. It makes no sense that the Indian government is not rolling it out.”

As Indians die from a preventable, curable disease, the patients say that there is no understanding of how much suffering is being inflicted on them. LYNSEY ADDARIO / GETTY IMAGES

The government's most common excuse is that it needs more evidence that the drug is safe. It had adopted this line of argument in response to Tripathi's petition as well. The researcher said that, when bedaquiline was being developed, there were only twelve thousand patients in the world who had been diagnosed with extreme drug resistance. "It is like asking for an amount of evidence that is impossible to generate," they said. "Countries had to start putting patients on the drug to generate evidence. Good quality of evidence can only be generated over time—that is how the field of public health works. With new data, the world accepted it, and, much later, India accepted it too. Patients are now getting better with bedaquiline."

The other excuse I heard during my reporting was that BPaL is a "foreign" treatment. It is not. "Pretomanid has been manufactured only in India," Sandeep Juneja, the senior vice-president for market access at the TB Alliance, told me. "From India, it has been exported to nearly eighty countries, so pretomanid manufacturing is benefiting TB patients outside India, as well as the Indian pharmaceutical industry. In fact, much of the development work done by TB Alliance was undertaken in Indian labs."

I sent questionnaires to the health ministry and the Central TB Division but did not receive a response. I also filed a right-to-information request with the Central Drugs Standard Control Organisation, asking about details pertaining to the stockouts of tuberculosis and HIV medicines, and whether any action had been taken against J Duncan and Centurion for failing to meet their contractual obligations. The CDSCO responded that it possessed no such information and that this was a matter for the state licensing authorities, even though I was asking about a centralised tendering process.

Sources in the health ministry suggest that the 2025 target is likely to be pushed back to 2029 or that the methodology for gathering data might be changed.

WHEN MODI ANNOUNCED that India would eliminate tuberculosis by 2025, he gathered unanimous praise for simply setting a target that was five years ahead of the global sustainable development goal. Over the past decade, while he declares victories over pathogens, the patients have vanished from his health policy, much like stains from laundry. One survivor told me, on condition of anonymity, that, when a group of them informed Rajendra Joshi, the deputy director general of the Central TB Division, about the situation on the ground, his response was, "nice of you to come here." Another survivor recalled being given two reasons for the government's failure: first, that it was a victim of its own success, since it had diagnosed too many patients, and, second, that patients around the world faced the problem of drug shortages. "It is bullshit," a member of the group responded.

As 2025 approaches, sources in the health ministry suggest that the target is likely to be pushed back to 2029 or that the methodology for gathering data on tuberculosis patients might be changed. "Uninterrupted supply of anti-TB drugs, forecasting, having buffer stocks and streamlining the procurement process is crucial," Blessina Kumar told me. "To deny patients with TB their rightful access to diagnostics, treatment and care is a crime. Not taking responsibility for lapses, so they can be addressed, only adds to that. So, no, India is not going to end TB by 2025 or 2030."

While the Modi years will be remembered for catastrophes such as demonetisation, the migrant crisis during COVID-19 and the abrogation of Article 370, it is his health policy that will cast the longest shadow over future generations. Even as millions of people continue to be infected by tuberculosis and HIV, the media and the government have been fixated on the blood sport of election campaigns. "There was a time when TB did get some attention in terms of money but, post COVID, we seem to have no interest in solving the real issues," Yogesh Jain said. "It is all about the optics."

"We need to move beyond political posturing and slogans," Chapal Mehra, the convenor of Survivors Against TB, told me. "We can understand that the government will find it hard to eliminate TB, but they can try to eliminate TB-related poverty by improving the public sector. Poor people are still going to the private sector and getting exploited. I sign letters, write columns, brief policymakers, but not enough changes on the ground. It is a movie-like situation—we are heard, but action isn't swift enough."

Modi was right, in a way, when he announced in Varanasi that India's efforts are a "new model" in controlling tuberculosis. The policide is indeed a new model. As Indians die from a preventable, curable disease, the patients say that there is no understanding of how much suffering is being inflicted on them. "Instead of eliminating TB," Ganesh Acharya said, "the government is eliminating us."

Vidya Krishnan is a global health reporter who works and lives in India. Her first book, *Phantom Plague: How Tuberculosis Shaped History*, was published in February 2022 by PublicAffairs.

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