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BOOK REVIEW

Tuberculosis: Finally, out of the shadows.

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Vidya Krishnan. *Phantom Plague: how tuberculosis shaped history.* New York, Public Affairs, Hatchette Book Group, 2022. 320 pages, Rs 1708 (hardcover), ISBN-13: 978-1541768468

Tuberculosis is a hidden disease. It is under-diagnosed, under-counted, stigmatised, largely a poor person's illness, and therefore not of much interest to the media. India has the burden of tuberculosis (TB) cases and deaths in the world with 26% of new cases and 34% of deaths in 2020 [1]. Yet, most of us are more likely to know someone with diabetes, heart disease, or cancer than a friend or acquaintance who has undergone treatment for tuberculosis.

Vidya Krishnan's *Phantom Plague* aims to take tuberculosis out of the shadows, as well as to lay bare the edifice of inequities behind this killer. While the subhead is "how tuberculosis shaped history", the book is actually about how the history of TB — as is the history of all disease — shaped by structural injustices in society that put some groups at greater risk of disease, and less likely to get treatment. The author writes an impassioned account of how class, caste and race violence and other marginalisation, in society and in medicine, have come together to create this crisis. The book is based on extensive secondary research supported by interviews with researchers, medical professionals, public health practitioners and patient advocates. It is addressed to a general readership.

Krishnan starts in the nineteenth century Europe when diseases were ascribed to miasmas and magic, and TB was a "phantom plague". The first few chapters take us through the intersecting lives of the men whose discoveries led to the understanding that certain diseases are caused by germs, and developed the tools to fight them — public health measures to reduce the risk of transmission, and drug therapies.

The next section looks at the conditions that drive the TB epidemic in India. Krishnan starts in Mumbai, with the findings of a study on an outbreak of drug-resistant (DR) TB in a government slum rehabilitation scheme. The city's brutal housing policy, by which the poor are forced into airless, lightless high-rise slums so that land can be freed up for more luxury buildings, has become a recipe for such outbreaks. Caste-based segregation forces Dalits to ghettos within ghettos, increasing already high risks of disease.

Other chapters describe how the government programme and private medical services have together failed the public. In a healthcare system dominated by an unregulated private sector functioning independently of an underfunded, unfriendly public programme, people with TB are not diagnosed promptly and treated rationally. Krishnan conveys the outrageousness of a situation in which patients see an average of three doctors and spend two months before getting a proper diagnosis, after which they are often put on expensive and irrational treatments, without appropriate drug sensitivity tests. As a result, we see progressive waves of drug-resistant TB, much of it unreported. A silent epidemic or a phantom plague.

The third major theme of the book concerns one of the biggest challenges facing healthcare today — the intellectual property regime that deprives large parts of the world of access to life-saving technologies including medicines, many of which have been developed with public support.

Krishnan takes us through a short history of intellectual property rights, from the Paris Convention in 1883 to the Trade-Related Aspects of Trade Intellectual Property Rights agreement; the Bill and Melinda Gates Foundation's use of philanthropy for patent protection and profit, and the benefits for Big Pharma and the countries of the Global North. Provisions to ensure access to new drugs through clauses for compassionate use, voluntary licensing, and compulsory licensing have failed. Pharma has used the "compassionate use" clause to avoid permitting voluntary licensing, and the Indian government has not used the compulsory licensing provision despite the pleas of patient advocates and public health professionals. Bedaquiline by Janssen and Delamanid by Otsuka Pharmaceuticals, the first new drugs for TB to be approved after 50 years, are part of the World Health Organization (WHO) guidelines as part of

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standard treatment for DR TB. Though India's caseload of multidrug-resistant (MDR) TB is among the highest in the world, only a fraction of these patients actually receive the drugs. Krishnan refers to the access to medicines campaign started in the 1990s by advocates for people living with HIV, and Cipla's revolutionary offer in 2001 to sell AIDS drugs at a fraction of the prices set by Big Pharma. One wonders if Yusuf Hamied would make a similar offer for TB drugs today. And, if he did, would the government support him?

Through the stories of three women with DR TB, Krishnan shows how the pharma industry uses patents to control prices and access to life-saving new drugs, and the government goes along. Piya Kumar was forced to go to Japan and apply to Otsuka Pharmaceuticals' for Delaminid under its "compassionate use" programme because it is not available through the government. Nandita Venkatesan was treated with an old drug known to cause hearing loss, when she could have been treated with other medicines, and Shreya Tripathi was told that Bedaquiline was the only drug that could save her, but she was ineligible for because she was not a resident of any of the cities where the government was administering the drug in a conditional access programme. Shreya went to court and in 2018, won the right to treatment, but by then she was too far gone to benefit from it.

Readers might have better understood some of the details in Krishnan's scathing critique if she had explained the programme's logic for certain decisions. These decisions, however flawed, may have been about more than bureaucratic apathy and contempt for the poor and powerless.

Antibiotic resistance, the natural consequence of widespread irrational drug prescriptions in the private sector, was already a problem when the Revised National TB Control Programme (RNTCP) was launched in 1997. The problem of growing drug resistance should have been addressed by the Directly Observed Treatment Short-course (DOTS) programme — based on WHO guidelines of the time — which introduced a standardised drug protocol and a system to ensure that people took them.

However, while directly observed treatment was a great concept in theory, the programme did nothing to address the problems patients faced in getting to the clinic — such as the cost of transport and wages lost, inconvenient clinic timings, rude and uncommunicative clinic staff — all of which contributed to patients defaulting. Second, those who had not completed treatment were given the same drugs, along with injectable streptomycin [2]. This protocol was part of the WHO guidelines in 1997, as there were only a handful of drugs approved for the TB programme at the time. Third, the RNTCP's thrice weekly drug regimen — again, following WHO guidelines — introduced for financial and logistical rather than medical reasons actually fuelled the growth of DR TB, and it continued a decade *after* the WHO recommended a daily regimen [3].

The question in the second and third cases is not the practices but the fact that they continued even after evidence emerged that they contributed to drug resistance. Likewise, toxic antibiotics, repurposed for DR TB as there were a few alternatives, should have been dropped as soon as better drugs came along. However, kanamycin continues to be used in the RNTCP [4].

Of equal concern, the RNTCP did not, initially, provide treatment for MDR TB patients. These patients, even when admitted into *government* hospitals for complications of DR TB, had to buy these drugs from the market. The government programme started MDR TB treatment only in 2007.

Some small errors in Krishnan's book should have been picked up in the course of a fact check. For example, the municipal ward where the organisation "Doctors For You" identified a cluster of drug-resistant cases is M-East, not Mumbai East. Mumbai's population at the time of the 1876 plague was 800,000, not 8 million, and in 2008, the number of housing units needed for the slum rehabilitation scheme in a city with a population of 18 million was definitely not 8 million.

There is an important gap in this otherwise comprehensive account of the drivers of the TB pandemic. One cannot talk about TB without talking about food deprivation. TB disease is activated by low immunity, and it is known that undernutrition affects immunity. Undernutrition is the "leading risk factor accounting for TB incidence" and is attributed to some 600,000 cases of TB disease in adults in India, more in rural than urban areas, more among scheduled castes, and more among the poor. Severe undernutrition is "a common risk factor for mortality in patients with TB in India." Those with HIV co-infection or DR TB do worse if they are undernourished [5].

Undernourished people hospitalised for drug reactions will improve due to the food they get in the hospital, but without access to good food once they are discharged, they face the same problems. They cannot tolerate the treatment itself, and may stop the medicines as soon as they feel better, increasing the chances of developing drug resistant disease. Of course, it is not just a matter of helping people adhere to treatment. People with TB in India are so severely undernourished that "…nutritional support should be considered an essential rather than optional part of treatment." [6]

Inadequate levels of calorie and protein consumption, consumption of poor quality vegetarian protein, and the fact that more than 70% of the Indian population cannot afford a nutritious diet [7] are the reasons that Indians have among the world's worst indicators of nutrition. Government policies such as a "targeted" public distribution system which does not provide sufficient protein, the under-funding of schemes such as the integrated child development scheme, a mid-day meal which does not

guarantee eggs to all children — all these contribute to the enormous crisis of malnutrition and, consequently, to the persistence of high levels of tuberculosis in India.

It is the government's responsibility to ensure universal access to nutritious food through multiple routes. This is both a necessity and a basic right. Of course, we do not need tuberculosis to tell us that.

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