



Experts fear a resurgence of leprosy in India

India declared the elimination of leprosy as a public health emergency in 2005, but a resurgence could be going unnoticed. Sophie Cousins reports.

When G Venu Gopal began to show visible signs of leprosy infection 50 years ago, he was forced out of his community in the southeastern Indian state of Andhra Pradesh. He was only 17.

"I had to leave my village and my studies to save my family and myself", the now 67-year-old said. "I didn't know anything about leprosy. My future was spoilt because of stigma and discrimination." Gopal left his village for Delhi, where he did not speak the language or know anyone. He soon realised he would only be welcome in a leprosy colony on the outskirts of the city where others like him lived.

Fast-forward five decades, Gopal still lives in the Tahirpur Leprosy Complex in rough conditions, with about 9000 people living with leprosy and their families. There are more than 800 colonies across India.

Gopal, vice president of the Association of People Affected by Leprosy, an organisation that works to improve the lives of those with the disease, says stigma and discrimination are fuelled by a misunderstanding about how leprosy is transmitted. Even though he has been cured for decades, people believe he is contagious.

"I wanted to be a doctor", he says, "but look, I'm stuck in a colony. A lack

of awareness about leprosy has created misconceptions about it. That's why you see all these colonies."

"The government is in a state of denial about the levels of leprosy in the country."

Such stigma propels people into a life of poverty and exile. Many hide their disease and go untreated because of fear of discrimination. Gopal knows he is one of the lucky ones because he does not have to rely on begging to survive, which is the harsh reality for many of those affected by leprosy.

India and leprosy

Leprosy, a chronic infectious disease caused by *Mycobacterium leprae* is transmitted via droplets from the nose and mouth and has an incubation period of 1–20 years. It primarily affects the skin, peripheral nerves, mucosa of the upper respiratory tract, and eyes, leading to disfigurement and nerve damage. Leprosy is curable with a multidrug therapy of dapsone and rifampicin. Clofazimine is also added for patients who have multibacillary disease, a condition diagnosed by a skin smear. The drug combination, which lasts between 6 months and 2 years, kills the pathogen and cures the patient. Early diagnosis and treatment can prevent disability.

In 2005, India announced the elimination of leprosy as a public health problem when the prevalence rate reached fewer than one person per 10 000 people at the national level. But experts now fear the announcement was premature.

"In 2005, while we were applauding ourselves, we did not look deep enough to see the regional variations. That, in itself, should have given us a pointer that this problem was far from

over", said Vineeta Shanker, executive director of the Sasakawa-India Leprosy Foundation, an organisation that focuses on creating economic opportunities for leprosy-affected people.

"The government is in a state of denial about the levels of leprosy in the country", she said.

Experts argue that the "forced elimination" of leprosy in 2005 diminished the country's ability to fight the disease and that the rhetoric led people to believe it no longer existed.

Vijay Garg, a leprosy expert based in New Delhi with 30 years' experience, said the 2005 elimination announcement was a mistake because "later, the government realised new cases are everywhere". He added that he sees new leprosy cases at Lok Nayak Jai Prakash Narayan Hospital in Delhi regularly, which means "the reservoir is still there".

Today, India accounts for 60% of the global burden of the disease worldwide. In 2016–17, there were 135 485 leprosy cases detected, according to the National Leprosy Eradication Programme. That translates to a prevalence of 0.66 per 100 000 people.

However, experts believe that this is an underestimation of the true number of cases. A sample survey conducted by the Indian Council of Medical Research between 2008 and 2011 found there could be as many as 250 000 new cases of leprosy in India each year.

In stark contrast to the official announcement 13 years ago, India's National Health Policy 2017—which will guide the policy direction of the country over the next decade—set elimination of leprosy as a "national target". It states that the policy "envisages proactive measures targeted towards elimination of leprosy from India by 2018".



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"In our enthusiasm to announce elimination, the government moved leprosy to our public health programme rather than to have a focused mission—a vertical mission—to tackle it", Shanker said. "Unfortunately, what this move did was dilute efforts on the ground. Suddenly, this huge force of people who are trained experts in identifying leprosy were lost. It went down in the government's priorities."

Mary Verghese, executive director of The Leprosy Mission Trust India, the largest organisation focused on the disease in the country, said that after elimination was declared the country moved to voluntary case reporting. As a result, between 2004 and 2007, research shows new case detection dropped by 75%. "Everyone thought leprosy was no longer there, so there was a reduction in resources and funding available", she said.

Henk Bekedam, WHO representative to India, said the country was a "priority country on leprosy based on the number of new cases and new grade 2 disability cases reported annually" to the agency. However, he said the integration of the leprosy programme into general health reflected the "appropriate public health strategy".

The leprosy burden is not carried equally

New analysis by Oommen C Kurian, a public health fellow at the Observer Research Foundation, an independent think-tank based in India, has found that, even more so today, leprosy remains a disease of the most marginalised and underserved populations in far-flung areas. India's leprosy burden is disproportionately affecting the country's indigenous communities—known as Adivasis—which constitute 8.6% of the population, he found.

In 2009, Adivasis accounted for 13.3% of new cases; in 2017, that proportion rose to 18.8%. In states like Gujarat, in western India, and Tripura, in the northeast, two-thirds of new

patients with leprosy are Adivasis. In addition, Kurian found that the number of districts across India with a prevalence greater than one per 10 000 had increased to 18.8% in 2017 from 15.3% in 2012. Although in 2010, there was no district in India with a prevalence of more than five per 10 000 people, in 2017, there were four, he said.

"India's leprosy burden is disproportionately affecting the country's indigenous communities known as Adivasis..."

"More than 18% of districts [across India] have a prevalence above the elimination target and it is increasing rapidly. We are far from elimination at the state and district level", he said.

Experts say that they are unsurprised the epidemic has become centralised among the most marginalised in India, where those infected by the disease have little or no access to health care.

"No one there [in the tribal areas] knows about leprosy. They are not getting treated so there is potential for it to spread", Shanker said. "We could be successful in bringing down the prevalence level to an insignificant level but a concentrated effort needs to be made across the whole country. Today we can focus on endemic areas, but what is non-endemic today may turn out to be endemic tomorrow. Without mass awareness, it will not happen."

Recognising it had no post-elimination announcement strategy, in 2016, the government began a door-to-door leprosy detection campaign. 163 districts were targeted for active case finding and, last year, 305 districts were targeted.

Data from the National Leprosy Eradication Programme show that the official number of new cases recorded every year since elimination continues to hover around 130 000.

As part of its revamp of the primary health-care system, the government has also committed to building

150 000 health and wellness centres across the country that will screen everyone for leprosy.

"It is critical that these health and wellness centres rebuild the workforce capacity so [health-care workers] will know how to suspect leprosy cases", Verghese said.

In 2016, WHO launched its *Global Leprosy Strategy 2016–2020: accelerating towards a leprosy-free world* to re-invigorate efforts for leprosy control. One of the key interventions is to ensure the prompt start of, and adherence to, treatment and strengthening surveillance for antimicrobial resistance, on a backdrop of growing concerns about rifampicin-resistant leprosy cases being detected in India.

Addressing stigma and discrimination

If stigma and discrimination are not addressed, leprosy will most likely persist. In 2016, India repealed one of its oldest discriminatory laws that sanctioned the arrest and segregation of people affected by leprosy into so-called leper asylums, but 119 laws still exist that discriminate against people affected by leprosy, Shanker said.

Health-care workers also need to be sensitised, says Shankar. "Leprosy patients will die but not go to a government hospital because it is so demeaning. They cannot lift the tablets and they fall on the ground."

"We have not kept the issue alive; we have pushed it more and more under the cover and as a result we've pushed people into the margins of society."

Fighting discrimination is crucial to enable people affected by leprosy to get off the streets and earn a livelihood, says Gopal. "Medical treatment is not enough. If you force people to beg, then you just fuel stigma", he said.

Looking forward, Gopal says, "I do not know what will happen. There are many new leprosy cases. Maybe we will succeed, but after my death."

Sophie Cousins