

A Stigmatized Reality

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Sapna of Dhar, Madhya Pradesh was HIV positive. She did not seek help and eventually her immune system weakened, making her prone to Tuberculosis. She could hide it no longer and now she lives in a deserted shack away from her kins with her husband and two children. Nobody plays with her children lest they should catch the disease.

An affluent family in Indore shunned their daughter in law, Neerja, on learning that she suffered from Tuberculosis.

In Bhopal, a 70-year-old couple when diagnosed with Tuberculosis was locked up in a room by their own sons. When a member of the health care department tried to intervene he was met with death threats. In Jabalpur, Manoj's wife left her husband only because he had Tuberculosis. In the area of Arif Nagar, Bhopal, Tuberculosis has led to three cases of filing of divorce.

The state of affairs in the rural tribal areas are far grim than the tales of the cities. Among the Korku tribe in the Khalwa block of Khandwa, MP anyone detected with TB, will not only be forced to live in the cattle's shed but almost has to live in exile. Recently, Haldu, a tribal woman of Vikrampur village had to face this banishment. It is believed that the excretion of the goats is a remedy for the TB hence, goats are being tied to the patient's hut.

Despite the development and progress, the above cases clearly depicts that the stigmas attached to Tuberculosis still prevails in the society. The fact is that a large number of population in India live with Tb. According to an official figure, around 10 lakh people die every year due to Tb. Ministry of Health and Family Welfare has released a data stating around 18 lakh new cases of Tb being registered every year. Nearly 3 lakh students have to drop out of their schools at a young age to take care of their parents sick with Tb only to be affected by the same.

The stigma around TB is one of the major cause for a highly discriminated life and leaves the patient with no option but to live in isolation. It therefore, becomes a difficult task for the state healthcare department to register these patients. Madhya Pradesh

accounts for 32,000 such cases which have not been registered yet where the TB patients are unknowingly transmitting the disease to others. A TB patient is capable of transmitting the disease to 16 other individuals in an year. And usually due to lack of awareness

600 "unclaimed" deaths every year

Soni, a 60 years old retired government employee sought treatment for TB at the State Hospital in Bhopal. Soni had been admitted for 7 days but his son didn't come to meet him once. When Soni contacted his son, his son shunned him for calling and said not to call again.

After one and a half months, when his treatment was nearly complete and was almost ready to go home, he gave his son's phone number to doctor Verma. Soni's son refused to take Soni back home.

"We have some respect in the society, there are kids in home, from now, this is his home" Soni heard this conversation between his son and doctor Verma and he passed away that afternoon.

Similar is the case of a sarpanch of a village near Bhopal, whose family left him alone.

A 17-year-old minor from Sehore district has the same story. He was admitted in this hospital and given a sum of 200 but now, there is neither money nor his family.

These all are the instances of 'experienced stigma'. Every month, the state TB hospital, Bhopal mark the funerals of an average of 3-4 unclaimed dead bodies. Around 40 unclaimed funerals in a year. Madhya Pradesh consist of 51 state TB hospitals. If one considers the average figure of the neglected patients in the hospital by their kins owing to the stigma of the disease as even 1, the annual figure would be 600.

Stigma manifests the 650 deaths from state TB hospital in a year into unclaimed dead bodies and forms an extensive number. Unfortunately, these numbers from TB hospital are not considered significant for the National Tuberculosis Report.

and misconceptions individuals are not aware of the fact that they are infected with TB.

In Madhya Pradesh, there are an estimated 216 patients of Tuberculosis for a population of 1 lakh. This implies that there must be 1,68,000 new patients every year but in the year of 2017, there were only 1,36,000 patients reported. However, in comparison to previous years, the number of unregistered patients is decreasing. Four years back, there were around 72,000 registered cases, the number has now decreased to half. In order to end Tb from the state and eventually from the country, the prompt recognition and documentation of the patients is essential.

60 percent of patients have concealed the disease

The research by V.K. Dhingra, director of New Delhi Tuberculosis Center (NDTB) and Shadab Khan, a social worker dealing in medicine which was published in the Indian Journal of Tuberculosis, in 2009, gives a clearer picture. Out of the 1977 registered cases, around 60% of the patients had concealed the disease from their friends and neighbors. The stigma around the “disease of the poor” is found evidently in the middle and the upper middle classes. The women patients are more susceptible to this discrimination than their male counterparts.

A research led by Dr. Surya Baali from the Department of Community and Family Medicine, AIIMS, Bhopal states that women mainly between the age of 18-30 do not come forward for the treatment of Tb, lest their marital life is sabotaged if the news goes public.

In defiance of such alarming situations, the Revised National Tuberculosis Control Program (RNTCP), a government initiative, hasn't taken any specific measures to address the stigmas and the misconceptions.

Experts say that with the early symptoms, counseling is crucial for the patient and the family both to make them aware of the stigmas and prejudices attached to the disease and its complications, and to make them confident and familiar with the disease till the completion of the medication and treatment. However, it is surprising that there are no posts for the counselor in the national, state and district level.

Atul Kharate, State TB official of Madhya Pradesh says that stigma is still a reality, and needs to be overcome. Also, puts up that to deal with the social stigma they have only the promotional materials (IEC).

Prime minister Modi has set a target to make India a TB free country by 2025. However despite various government efforts India constitute an extreme figure of TB patients. Thus, for India to overcome the Tuberculosis and to have an inclusive society, there is a strong need to attack the stigmas, prejudices and discriminations.

A collective empowerment of people and communities is fundamental to fight against TB but unfortunately it is a long road for us.

