

Voices from TB



Picture by Somya Parikh, used with permission of the Lilly Foundation

by Chapal Mehra

Over the last several years, Tuberculosis or TB has come to be recognized as one of India's severest health crisis. We know about the impact of TB - it kills close to 1000 Indian's every day, causes extensive human suffering, is an engine of poverty pushing families and communities into poverty.

Yet rarely, do we hear from those most affected by TB- patients, survivors and their families. After all, surviving an infectious disease like TB is both an individual and a social experience. Why then is TB narrative in India primarily dominated by experts, doctors and political and human rights rhetoric?

When we first conceptualized this book, these thoughts were paramount in our minds. We wanted to understand the lived experience of individuals and families affected by TB, but in a way that it was true to the lives described by them.

We wanted to record stories of patients in a way that would challenge the stereotype of the TB affected as suffering and powerless individuals. We wanted to show the grit, determination and triumph of their spirit in the battle against TB. At the same time, we also wanted to demonstrate the numerous challenges that continue to face those affected by TB irrespective of whether they seek care in India's public or the private sectors.

While not considered 'reliable' evidence, survivor narratives undisputedly invaluable insights into the mental, and physical experience of fighting any disease. Thus, stories of the TB affected provide information on how patients interact with doctors, health systems, in families and communities. These insights are critical if we wish to achieve the oft used term of 'patient-centred care'.



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The few stories of drug resistant TB survivors in this collection show us the multiple challenges and neglect that often leads to patients becoming drug resistant. Issues of delayed diagnosis and treatment, unbearable side effects and insufficient counseling

and support emerge as important factors. This is particularly relevant as our ability to address DR TB in India as public awareness on the issue remains questionable.

Perhaps the most important yet neglected challenge that emerges from these stories is that of TB related stigma. Irrespective of economic and social backgrounds, literacy levels or awareness, most TB affected chose to remain silent about the disease to extended family, friends, and their communities. In particular, women continue to hide their disease due to fear of social ostracism, discrimination and abandonment.

In the end, these stories represent a charter of demands from survivors that have faced numerous challenges while fighting TB. For some, it has been a matter of survival for some others a question of sanity. It is important for all of us, but particularly those in power, to understand their needs and address them. Hopefully this will happen in the years to come.

Read the Voices from TB book [here](#).

The book has been authored by Chapal Mehra, a public health specialist whose work on the book was supported by the Lilly Foundation. Text and images are used with permission of the Lilly Foundation.