

## Surviving TB: What can we learn and do better?

Deepti Chavan, [Survivors against TB](#)<sup>5</sup>

*In order to strengthen our fight against tuberculosis (TB) we need to make sure that the response in TB care is person-centric and tailored towards those affected by TB. One size fits all cannot be the norm in TB care especially when this disease is already so complex.*

*We demand the following for every person diagnosed with TB:*

- Access to free quality TB care irrespective of whether they seek care in public or private sector.
- Access to free drug susceptibility testing (DST).
- Access to shorter and safer drug regimens.
- Access to counselling and mental support.

### DELAYED DIAGNOSIS COST ME MY LUNG:

IN MY SEARCH FOR TREATMENT, I MET WITH MANY PRIVATE PROVIDERS AND FOUND THAT MOST OF THEM WERE NOT FAMILIAR WITH THE TREATMENT GUIDELINES. IN MY PARTICULAR CASE, THE DOCTOR KEPT CHANGING ANTIBIOTICS EVERY TIME I HAD ANY REACTION TO THE PREVIOUS ONES PRESCRIBED. THIS SOMETIMES HAPPENED WEEKLY! ALSO, HE ONLY ADVISED ME TO GET A DST DONE AFTER A YEAR, WHEN THINGS HAD GOTTEN WORSE! BY THIS TIME, THE ONLY CHOICE I WAS GIVEN WAS TO GET THE AFFECTED PART OF MY LUNG REMOVED, AS I WAS ALREADY RESISTANT TO MOST OF THE AVAILABLE MEDICINES!

--- Deepti Chavan

In India, like many other high burden countries, most patients seek healthcare first in the private sector. So, it's imperative that we engage private sector providers in the fight against TB. This will reduce diagnostics delays, inappropriate treatment, incomplete treatment, reduce transmission of disease and improve overall quality of care. All healthcare providers need to be aware of drug resistance, and work to prevent it. They need to offer the best quality treatment and care to patients – it is a patient's right.

Please allow me to outline three key concerns I want the TB care community to talk about more:

a) Stigma and mental health; b) socio-economic determinants of TB; c) diagnostic delay and treatment side-effects.

### Stigma and mental health

*When I was fighting tuberculosis, I was so lucky to have my family's support. However, I constantly felt guilty about putting them at risk of getting infected, and having to sacrifice their lives for me. Many patients carry this guilt and fear inside them. If we want to End TB, we need start talking about these issues! TB is not just a physical disease, it also affects a patient's mental well-being<sup>1</sup>. We need to sensitise doctors about the mental health effects of treatment and make sure counselling is offered to every diagnosed patient. Programs need to ensure that nurses and psychologists are linked to help patients in need. TB survivors are also an excellent resource in counselling patients in distress and could be recruited (and paid) by TB programs to help patients. More open communication will also help address stigma around TB, not just for patients but also for anyone affected by TB, or working in TB<sup>234</sup>.*

*We at ‘Survivors against TB’ have a patient support group where patients on treatment can ask questions and survivors try and help them out by addressing their queries! It really helps them a lot!<sup>5</sup>*

#### Healthcare coverage and socio-economic determinants of TB

*I was lucky my parents were able to sell jewellery and take personal loans to support my treatment. But many patients are not so lucky!! Socio-economic factors have a big role in ending TB. Currently the TB programs are heavily focused on treating patients visibly sick with TB – and we are often missing the poor people with TB (or latent TB) who cannot afford the tests and medicines. It is good to see discussions now more on financing of tests and treatment through universal health coverage. But we also need to focus on TB prevention to help those who are at the risk of getting TB. We need to go beyond giving treatment to those who are diagnosed with TB, and actively start testing high risk groups such as people who smoke or have other co-morbidities such as diabetes or HIV. Their lungs are weaker and they are more vulnerable to developing the TB disease. TB doesn’t discriminate between rich or poor, young or old, men or women so why should there be any discrimination when giving access to diagnosis or treatment – in fact we need to get involved in addressing the socio-economic determinants of TB to prevent the risk-factors: poverty, smoking, air-pollution, nutrition and malnutrition, etc.*



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#### Diagnostic delay and treatment side-effects

*I had TB and my diagnosis was delayed for considerable amount of time! I was put on wrong treatment and when everything else failed my doctor asked me to get a DST done! If I had gotten a DST sooner, my lung could have been saved! I feel like I was a guinea pig for doctors experiments and endless trials and errors in toxic drug regimens!*

Notwithstanding that anti-TB medicines have horrible side effects. The treatment is such that patients often find dying is easier than completing the treatment. Why is the healthcare system not sufficiently bothered about people losing their hearing or vision? If we have safer drugs available which are less toxic and have fewer side-effects then what’s stopping us from using them? Those needing treatment should have access to safer medicines as soon as they are available for use!

So, a message to the policymakers: next time you sit down to frame guidelines and policies, please take a moment and think. Put yourself in the shoes of the TB patient or a loved-one (god forbid). What if someone close to you gets diagnosed with TB.... What TB care would you or your loved-one want to receive? If you really want to know what’s not working in the TB program all you need to do is have a discussion with those affected by TB. I guarantee you that by the end of the discussion you will not only know the problem that exist in the program but also their possible solutions. After all we have survived the disease and we exactly know what works and what doesn’t.



THE ONUS FOR GETTING TB TREATMENT IS  
PLACED ON THE PATIENT BUT WHEN  
DECISIONS AND POLICIES ARE MADE THE  
PATIENTS ARE CONVENIENTLY LEFT OUT.

Deepti Chavan

**In order to fight this menace we really need to put those affected at the heart of TB response.**

<sup>1</sup>Is depression contributing to low global cure rates for multi-drug resistant TB?

<http://www.stoptb.org/webadmin/cms/docs/Blog%20WITH%20NEW%20PIC.pdf>

<sup>2</sup> STP TB Stigma Assessment - Implementation Handbook, November 2019

<http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Implementation%20Handbook.pdf>

<sup>3</sup> STP TB Stigma Assessment - Data Collection Instruments, November 2019,

<http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Data%20Collection%20Instruments.pdf>

<sup>4</sup> STP TB Stigma Assessment - Data Entry and Analysis Workbook, November 2019,

<http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Data%20Entry%20and%20Analysis%20Workbook.xlsx>

<sup>5</sup> <http://survivorsagainsttb.com/En/>