

Tackling TB stigma – a necessary step toward humanising TB



Stigma has long been recognised within the tuberculosis (TB) community as a barrier to ending the disease. It is a complex and challenging issue involving institutions, communities, and societal attitudes. The global TB and HIV epidemics are both worsened by stigma, incited by their association with poverty, social marginalisation, and the risk of transmission and death. But what is being done to confront it?

Speaking ahead of World TB Day on 24 March, Blessina (Blessi) Kumar - CEO of the [Global Coalition of TB Activists](#) and an elected Board Member for The Union since October 2016 - is adamant that things must change in the TB community in how it prioritises stigmatisation issues.

“Stigma around TB is nothing new. **In my work, I’ve seen first-hand** that the challenges of stigma create a huge barrier to accessing care and treatment. **When you’re on the outside, you don’t understand what stigma is.** We need to understand that self-stigma doesn’t happen on its own. It happens because of the surrounding environment that is stigmatising and causes those with TB to start stigmatising **themselves.**”

Self-stigma occurs when an individual begins to internalise attitudes that can include shame, disgust, and guilt. These can result in withdrawing from normal social interactions, shunning personal relationships, even avoiding leaving the house, or adopting risky behavioural patterns. The negative psychosocial consequences can, in turn, include depression, anxiety and loneliness.

For these reasons, Blessi says it is essential that the affected community drives the conversation and educates people who had never had TB on what living with the disease – **and people's reactions** to it – is really like. The answer has been, in part, for those who have experienced stigma to own the conversation by a retelling and sharing of their experiences, to create understanding.

Out of these aims, came 'Community Chitter Chatter' – a weekly conversation with TB survivors from around the globe by the Coalition of Global TB Activists. These conversations not only highlight the difficult journeys but also solutions from the **survivor's** perspective.

The first 10 conversations are with women and Blessi says, **"We** wanted to understand how women particularly face stigma and what they think about self-stigma. No woman stigmatises themselves without reason. Lack of correct information causes fear and fear leads to a stigmatising environment. We need to be careful that, when dealing with self-stigma, **we don't stigmatise** women even further. We must create an enabling environment around them that is positive and accepting and that reinforces the person – rather than focusing on the disease".

The impact of the environment and prevailing attitudes particularly resonates in some of the stories. Blessi explains: "If you read the story about Prabha*, she says she was so afraid that she might transmit TB to her husband, that she had no physical relationship with him for almost a year."

She continues, "In India, if you're **a woman, you already face stigma, if you're a woman and you're poor, it's a double stigma**. If you're a woman, you're poor **AND have TB, it's triple stigma**. And this causes differences in how people - and services - perceive the individual experience of living with TB. The **healthcare world's attitude towards you is different, no-one** actually listens to you, so service delivery stigmatises you."

Blessi has campaigned for roles to be reversed, with people who have experienced discrimination being at the forefront of driving change.

"I would like people who have been affected by stigma to be influencing decisions about how it should be addressed. There is no easy recipe for tackling stigma, it is about changing the **behaviour of society and that's not going to happen overnight**. It needs to start with, not only addressing TB in a way that upholds the rights of the person but focussing on respect for women. **It's linked to elevating the** position of women in society, the decision-making power that women have."

So how can the TB community contribute to change? For Blessi that is straightforward enough. **"We must** talk to the people who are affected, let them lead the response. In the HIV movement, there was regular training for different levels of people, whether you were a government official or a medical doctor, everyone went through the training to understand what HIV was and how it impacted people who experienced it first-hand."

She adds, "The TB response is very different, **it's** very bio-medical and things like stigma are not given prominence. If you read the stories in Community Chitter-Chatter, people are

saying over and over again that it needs the involvement and engagement of people like them. **We can't afford to not listen to this.**"

A key moment for community involvement is in the preparation for the UN HLM on TB, planned for September 2018. For Blessi, the community voice should be central to political engagement, not as an add-on or in isolation.

"There is no more powerful message than the experiences of people who have lived and are living with TB. This must be central to every related agenda, whether it's the drugs, the access, the diagnostics...stigma is central. The main narrative has to be from the point of view of people who are affected. It's not easy to achieve this because people don't want to step back and push the community forward. The space for the community is being taken by organisations and most do not necessarily represent the community's best interests."

She adds, "I want the TB world to recognise that, as long as we only focus on the bio-medical, that alone is not going to end TB. We need to work at all different levels and, right now, the level at which we need to work – the community level – is missing. The person has to be central to the TB response. Only then will policies, drugs, diagnostics be better, only then will the understanding created by the personal experience of those living with – and who have survived – TB, create the momentum for more investment and funding into the disease. If we all think of the person and what is best for that person, the chances are we could actually deliver the best for them. That is core to ending TB."

Community Chitter-Chatter:

TB survivor, *Prabha Mahesh, in an interview for Community Chitter-Chatter, says:

"I had a lot of fear because of the physical aspect of the disease – although I had extra pulmonary TB, my doctor still told me that it was contagious, and I had to be careful not to spread it to others. I had so much guilt, because I feared I would spread it to my loved ones and I thought the solution was to distance myself from home. At my workplace, I faced a lot of stigma. People no longer wanted to share my lunchbox, they would avoid me. My father too asked me to not tell anyone I had TB."

Read Prabha's interview and stories from other TB survivors, in [Community Chitter Chatter](#)

Read more on TB and stigma: [Ethics Guidance for the Implementation of the End TB Strategy](#)– World Health Organization