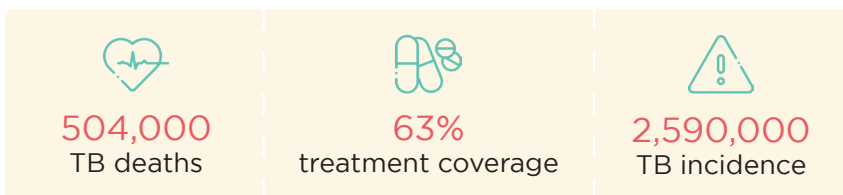




Tuberculosis & Stigma

TB Burden: India 2020



What is TB?

TB is an infectious disease caused by the Mycobacterium Tuberculosis bacteria. Since TB is an airborne disease, anyone who inhales the bacteria can get infected with TB. A person with TB infection usually develops the TB disease when his or her immunity is lowered. Poor nutrition, diabetes and HIV are some of the risk factors for TB, as they all lower a person's immunity.

What is Stigma?

WHO defines stigma as a mark of shame, disgrace or disapproval, which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society.

Stigma harms the livelihoods and health of individuals, and their families who experience it. It also severely hinders TB response. Stigma exacerbates the medical and social hardships of TB and acts as a barrier to accessing treatment, care and support; people who fear losing their jobs, their loved ones, or being kicked out of school or their homes because of TB are less likely to seek testing and treatment, making the already challenging response even more difficult. When the surrounding environment is stigmatizing and discriminatory, it begins to push those with TB to stigmatize themselves. Stigma and discrimination are not only human rights violations, but they are also a fundamental cause of population health inequalities. To end TB, everyone must recognize it as such and work together to eliminate TB stigma.

Types of Stigma



Internalized or self-stigma: TB-affected individuals may absorb negative stereotypes and behave accordingly, blame themselves, while also detaching themselves from friends and loved ones.



Anticipated or perceived stigma: The worry that one will be devalued after a TB diagnosis, which is often a result of observing others being stigmatized, may delay people from seeking and returning for care, or impact adherence to prescribed medicines.



Enacted or experienced stigma: A range of stigmatizing behaviors or messages enacted or propagated by others that are experienced by persons with TB and their families.



Secondary stigma: Caregivers, friends or family members may expect negative attitudes or rejection because of their association with persons with TB.



Community or public stigma: Negative attitudes, beliefs and behaviors held by the wider community – neighbors or co-workers in particular – or general public. This is closely related to anticipated stigma.



Structural stigma: Laws, policies, media and institutional architecture that may be stigmatizing, including societal conditions, cultural norms and institutional practices that constrain the opportunities, resources and wellbeing of TB affected populations.

Drivers and Facilitators of Stigma

- » Fear of getting infected with TB
- » Prejudice about the person with TB
- » Belief that TB will not affect me or my family
- » Belief that stigmatizing behavior is the social norm



REMEMBER!

Anyone can get TB

TB is curable

Risk of infection is reduced significantly when a person with TB starts treatment

TB does not spread genetically, or by touching, hugging, or sharing food with a person with TB

Reasons to Invest in Reducing TB Stigma

- » Higher acceptance and utilization of NTEP services
- » Reduced catastrophic costs and better use of resources
- » Better realization of India's goal of TB elimination

Manifestation of Stigma in Communities

- » Persons with TB anticipate stigma and hide the disease
- » Persons with TB have limited access to care and support
- » Persons with TB are segregated, neglected, and isolated; sometimes, they are even expelled from home
- » Mothers with TB are separated from their children, even prevented from breastfeeding infants

- » Persons with TB are blamed for bringing bad luck
- » Persons with TB delay seeking care, or seek care from unqualified practitioners to avoid stigma
- » Persons with TB are excluded from public places and resources such as water, play areas, community centers, etc
- » Social circles of persons with TB remain prejudiced, even after TB is cured

Manifestation of Stigma in Workplaces

- » Co-workers are afraid to mingle with persons with TB
- » Persons with TB are directly or indirectly told to not wear masks or take medicine at workplaces, and to hide their TB status
- » Persons with TB are not provided with necessary leave
- » Persons with TB are denied work opportunities, or promotion, or are pressured to resign, or are terminated from employment
- » Persons with TB face long-term stigma even after successful completion of their treatment

Manifestations of Stigma in Healthcare Facilities

- » Not providing adequate information about TB, and discouraging information seeking by patients and their attendants
- » Not touching patients during physical examination, or communicating through body language that the patient should be avoided
- » Denying in-patient care for persons affected by TB even when it is needed
- » Generalized unfriendly behaviour of health care personnel towards people affected by TB

Possible Outcomes of Ending TB Stigma



- » General population is legally protected against stigma and discrimination due to TB through enactment of laws and policies that are adequately strengthened to be more effective
- » General population is aware that TB is curable, and that its transmission may be prevented
- » Persons with presumed TB seek early healthcare without fear of stigma or discrimination
- » Persons with presumed TB and persons with TB disease, and their families, receive support along with high-quality care, and live without the fear of stigma and discrimination
- » Persons with TB disclose their TB status to their families and close contacts so that they may be supported through the treatment, and the close contacts may be screened and tested

Voices from the Field

“Our biggest fear was how people would react to our daughter’s illness... We avoided telling anyone... We did not want our family to get ostracized, but it’s difficult to hide... We did it to protect her...” - a father

“I had an effective team member with TB. He hesitated to seek leave. When he did, with great difficulty, I gave him 2 months... But, other team members felt I should replace him as it’s not OK for him to rejoin...” - a supervisor

“My wife [who has TB] is the cause of additional expenditure.” - a husband

“I was so scared when my son was diagnosed with TB. I thought he would die” - a mother

Community Led Monitoring

***monitoring:** to check, record or test something regularly for a period of time to improve current and future management of outputs, outcomes and impact.*

Community Led Monitoring is a process where communities take the lead to routinely monitor an issue that matters to them by:

- » Identifying their top priorities
- » Creating indicators to routinely track those priorities
- » Collecting data
- » Analyzing results
- » Sharing insights from the data with a larger group of stakeholders

Communities then work alongside policymakers to co-create solutions to the problems they have identified. TB affected communities need to come together and demand competent support systems for CLM to ensure the elimination of TB stigma.



Frequently Asked Questions

1. I am a Pradhan. How can I support the TB patients in my community?

As a Pradhan, you can “adopt” persons with TB and their families by providing physical, medical, emotional, and/or financial support, thus ensuring a stigma-free pathway to full recovery.

2. I am a PRI leader and I have noticed that some employers are discriminating against TB patients. What can I do?

You can use your influence to encourage workplaces to establish policies that prevent and address discrimination based on the legal and technical guidelines of India. You can also encourage employers to create treatment support groups at large workplaces or link TB affected workers to other such groups, ensuring that issues concerning persons with TB are heard and addressed.

3. Are community outreach activities enough or do we need to supplement these efforts with other means?

Community outreach activities are crucial but you can always supplement these efforts. Community Health Workers and TB survivors can advocate with block and district level officials to amplify TB issues through TV, radio and print media. First-hand stories of persons with TB, their inner circle, and of health care providers and community frontline workers can also be used. All these activities should focus on offering solutions to problems faced by persons affected by TB.

4. I am a Community Health Worker. How can I help persons with TB in my community to address self-stigma?

As a Community Health Worker, you must support community members in accessing care and treatment while also ensuring

that they feel supported through the treatment process. You must work to improve awareness about TB and its treatment - duration, medicines, their common side effects, etc. - thus enabling persons with TB to become TB literate.

Hold community meetings to improve awareness on the importance of reporting persistent side effects to concerned medical personnel and on seeking timely care for them.

Arrange community outreach activities to disseminate messages delivered by persons who have or had TB. Additionally, disseminate messages boosting self-confidence and the belief that TB will be cured, including messages that prevent or dispel fear of having to drop out of school/college, losing employment, friendships, relationships, etc., and of fear that promotes self-stigma and perceived stigma.

Encourage TB patients to ensure good nutrition, cessation of smoking, cessation of alcohol consumption, testing for diabetes and HIV, etc.

Talk to community members to encourage cough hygiene in a positive way, and encourage the use of masks when the person with TB is potentially infectious.

5. I am a Community Health Worker. How can I engage religious leaders in my community to join the fight to end TB stigma?

Identify, educate, train, and create a federation of TB-affected persons and religious leaders to work together. Disseminate messages that encourage community influencers to reassure persons with TB and their inner circle that they will be supported in their struggle to overcome the barriers to accessing quality TB care.

6. I am a Community Health Worker. What can I do if a family member is discriminating against a TB patient?

As a Community Health Worker, you should always address the genuine fear of infection, especially among those living in the same household. Additionally, spread messages like, “risk of infection reduces when a person with TB starts treatment”.

Talk to the family members and friends of the person with TB to share messages on how, and to whom, to reveal a person’s

TB status, thus optimizing support without increasing the risk of being stigmatized.

Disseminate messages that encourage contacts of persons with TB, especially children and high-risk contacts, to seek screening and testing, and accept preventive treatments if needed.

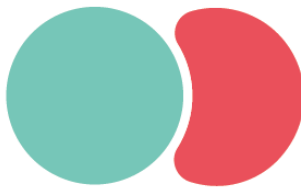
7. I am an ASHA/Community Health Worker/ANM etc. What can I do to end TB stigma in my community?

You have a unique position in the community. Use your closeness with the community to advocate for TB stigma eradication. Here are some actions that you can take:

- a. Disseminate messages that help prevent TB, reduce its spread, and encourage early diagnosis, treatment compliance and treatment completion. Dissemination of correct information reduces stigma. You can use messages like
 - » Anyone can get TB
 - » TB is curable
 - » Risk of infection reduces when treatment starts
 - » TB does not spread genetically or by touching a person with TB or by sharing food, utensils or clothes
- b. Inform people on where to seek health care in their vicinity
- c. TB survivors can also play an important role in influencing people, especially those with TB and the members of their inner circle.

8. I am a TB survivor. What do I do if health care providers in my area are discriminating against persons with TB?

Advocate for capacity building of health care providers on the use of soft skills that include suitable tone of voice, counselling techniques, avoidance of stigmatizing language and euphemisms. You, as a TB survivor, can also participate in capacity building of health care providers on the use of these soft skills. Encourage health care providers to openly discuss TB with persons with TB and their inner circle. You can contact your block/district level TB officers and PRI leaders.



Central TB Division

Ministry of Health & Family Welfare

New Delhi

www.tbcindia.gov.in