Tuberculosis & Stigma

learning4impact

1 IN 4 PEOPLE WITH TB IN THE WORLD LIVES IN INDIA

In 2017, 423,000 Indians died due to the disease[1].

TB is curable- but success rates depend upon timely and accurate diagnosis and treatment. Stigma can be a significant barrier to this and hence it is a challenge in ending TB. According to data collected by the Global Coalition of TB Activists across Asia Pacific and Africa, stigma and discrimination are some of the biggest barriers to accessing and providing care.

What is stigma?

Stigma can be defined 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 (WHO 2001).

Why is TB stigmatised?

- **Lack of overall awareness and understanding of TB**
- **Perceived risk of transmission of the disease and lack of knowledge on routes of transmission**
- **TB perceived as a marker for HIV positivity**
- **Lack of knowledge that TB is curable**
- **Communities may believe that infected individuals must have done something to deserve being infected[2].**
- **Perceived associations of TB with malnourishment, poverty, poor nutrition, low socio-economic class**

"I had to hide in the toilet in school while taking medication due to fear of stigma and discrimination. While I had a support group for HIV, I never had one for TB."

Chinmay Modi
TB/HIV Advocate, India

Perpetuating Stigma

Stigma occurs at different levels. It can be perpetuated

BY THE COMMUNITY

BY CLOSE SOCIAL NETWORKS

BY INSTITUTIONS (including healthcare providers)

MAY ALSO BE SELF-PERPETRATED (stigma internalised by those affected)

Stigma also operates in different settings- at home, at the workplace, in healthcare facilities, community/social spaces, etc.- and through relationships, which are linked to power and identity.

How does stigma operate?

Stigma may be

Perceived (or anticipated)

Experienced (or enacted)

Self-stigma

Stigma, whether perceived, experienced or self-stigma, affects a TB patient's experiences and behaviour across different settings. The alienation caused by stigma is a major contributor to the 'suffering caused by TB', minimising which is one of the WHO End TB goals.

From a system perspective, stigma negatively impacts outcomes at various points in the cascade of care for each individual, resulting in delays in health seeking behavior, delayed diagnosis and treatment initiation, and incomplete treatment. At the population level, it acts as a barrier to active screening in the community, contact tracing , as well as preventive activities[3 4].

'Persons with TB or presumed to have TB continue to be subjected to stigmatising language (eg, 'TB suspects', 'defaulters'), mandatory screening, testing and disease notification systems that lack privacy, contact investigations that label index patients, airborne respiratory isolation that prolongs their social isolation, directly observed treatment (DOT) that impedes individual autonomy, and in rare but relevant cases, legal detention and even incarceration of those who refuse or stop treatment.' - Daftary, A. et al, 2017.

Men and women both experience stigma associated with TB, but differently. In general, men report the most significant impact of TB stigma to be on their economic prospects, which include job loss and reduced income. While TB stigma also affects their financial status, women more often report concern that TB stigma will adversely impact their marriage prospects or that their families will shun them[5].

"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. At my workplace, I faced a lot of stigma. People no longer wanted to share my lunchbox, they would avoid me. My medical officer at work advised me not to tell anybody that I had TB so that there won't be any repercussions".

Prabha Mahesh
Extrapulmonary TB Survivor, India

TB stigma is experienced more strongly by certain subpopulations, including women, migrants and refugees, individuals living in rural areas, transgender persons and people with lower education levels[6]. Groups that are heightened risk of developing TB are also at heightened risk of stigma, including miners and indigenous peoples. The increased vulnerability of these groups to stigma interlocks with other forms of stigmatisation (as for migrants), with their and their community's awareness about TB, and with their susceptibility to the effects of discrimination (as with young women).

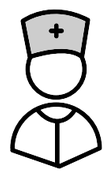
"During my TB treatment, my family would avoid coming near me. I was cured in 2014 and thereafter started working towards TB awareness. That's when their behaviour towards me and others with TB started changing. They now welcome people with a smile whenever someone from the TB community comes to visit me"

Mangra Khariya,
TB champion, Jharkhand

Breaking the barriers of stigma: Best practices

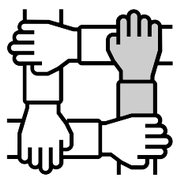
Awareness campaigns by TB champions:

Awareness campaigns by TB Champions in Jharkhand and other states have met with some success in addressing TB related stigma and discrimination (presser, June 25, REACH).



Role of Health Care Workers (HCW) in reducing stigma:

Nurses as providers of emotional support in Peru contributed to reduction in stigma[11]. Training workshops for HCWs in Taiwan indicate the efficacy of such interventions in eliminating stigmatization of TB by first-line workers[12].



Support groups to reduce internalized stigma:

Studies conducted in Ethiopia[7] and Nicaragua[8] indicate that TB clubs improve confidence, reduce stigma and positively influence a change in community attitudes to TB. A psycho-social support group intervention for MDR TB patients in Peru yielded similar results in enabling psycho-social rehabilitation after treatment[9].

Lessons from the HIV experience suggest that solidarity groups enable a shift from 'awareness-raising' to 'consciousness-raising', which empowers survivors to act in the face of adverse environments[10].

Proper information dissemination is critical:

It is important to disseminate TB related information accurately and accessibly. A study conducted in Nigeria indicates importance of messaging. In the study, stigmatizing attitudes worsened, which the study attributed partly to the Community volunteers involved in the study, who are not trained health workers. The CVs received a large amount of new knowledge themselves during a 2-day training and may not have fully understood the cause, transmission, signs, and cure of TB in order to effectively communicate them[13].

Other interventions:
- Maintaining privacy in all interactions with vulnerable populations
- Respectful and compassionate dealings with patients
- Workplace interventions

Gap Areas

The evidence indicates that there is a need for multivalent stigma interventions that need to be rigorously evaluated[14].

Tools to measure and track stigma – can yield data that will help design anti-stigma interventions. The toolkit developed by the Stop TB Partnership (not officially published yet) is an attempt to enable the measurement of stigma.

Stigma mitigation is not yet included as a cross-cutting approach in all interventions – so far it is treated as a standalone activity. Building it into training for healthcare workers, e.g. would increase effectiveness of the messaging.

Tools

- Every Word Counts
- Childhood TB and Stigma
- Women and Stigma
- STOP TB Partnership Stigma Assessment Handbook (To be released soon)

"I lost my job as a front desk manager – they told me that they didn't need me anymore and said I had become very thin and I should rest at home"

Mona Balani
TB Survivor & Champion, India

"My family members used to kick the plates from which I ate food. I used to cover my face as I walked around the house. If I sat somewhere, others would sit at a distance."

Jaganath with his wife Aarti
TB survivors & Champions, India

"I hid the fact that I had TB from colleagues at my workplace, some family members and friends in the community. I felt that people would criticise me for being sick with TB. Those who knew would mutter among themselves. They spoke not just about me but about my whole family It was tough to manage at my workplace too because I felt that people would not speak to me for fear that I would infect them or would end up getting fired from my job".

Fabiola Janet Rojas Coyca,
MDR TB Survivor, Peru

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