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The Isolating Walls of Stigma Surrounding Tuberculosis

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Abstract: ***Tuberculosis is a serious condition caused by Mycobacterium tuberculosis. Tuberculosis (TB) patients face pervasive social stigma and discrimination, exacerbating physical suffering and hindering disease control. Misconceptions, fear, and cultural norms fuel this stigma, leading to social isolation, delayed diagnosis, poor treatment adherence, mental health issues, and economic hardship. Discrimination manifests in various forms, including social exclusion, employment and healthcare biases, and educational and housing restrictions. To combat TB effectively, it is crucial to address underlying stigma and discrimination through education, empathetic healthcare, community engagement, and policy changes, promoting inclusivity, empathy, and human rights.***

Keywords: Tuberculosis, TB patients, stigma, discrimination, health, healthcare system, treatment

1. Introduction

Tuberculosis (TB) is a treatable disease, but it is still the leading cause of death worldwide, with millions of new cases and deaths each year. Despite significant advances in diagnosis, treatment, and prevention, TB continues to be stigmatized and discriminated, hampering efforts to combat the disease. The discrimination and stigma associated with TB are numerous, including social isolation (people may be isolated from their peers), isolation due to fear of contagion and behaviours that disadvantage delaying diagnosis and seeking treatment which can have serious health consequences. Our goal is to identify and advance new ideas that can effectively address and overcome these issues by sharing in-depth research, personal experiences and diverse perspectives from a variety of stakeholders in the region, we aim to create a harmonious and supportive environment for everyone living with TB. Finally, our efforts to make a positive impact in global advocacy are focused squarely on lung disease.

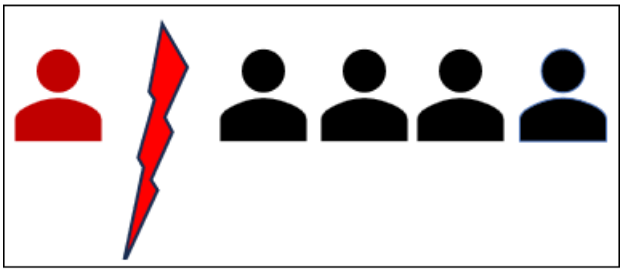
TB and Stigma:

Patients have compromised immune systems and face stigma. Goffman described stigma as "an attribute that is deeply discrediting" that demeans people "from a whole and usual person to a tainted, discounted one [1]"

This could have serious repercussions for tuberculosis sufferers in the community, at work, and at home, among other social settings. Research carried out in many contexts has demonstrated that 42% to 82% of tuberculosis patients encounter stigma. Thus, one of the main barriers to tuberculosis prevention and control in the modern world is the stigma attached to the illness. [2]

According to World Health Organization, Stigma is a mark of embarrassment, shame, or disapproval that makes someone unwelcome, discrimination-prone, and unable to participate in many social activities. The response to tuberculosis is severely hampered by stigma, which also negatively affects the lives and health of people who are affected. People are less likely to get tested and treated for tuberculosis because they fear losing their jobs, relationships, homes, or schools as a result of the disease, which worsens an already difficult prognosis.[3]

TB Stigma in India:



Stigma is when you are perceived negatively by someone.

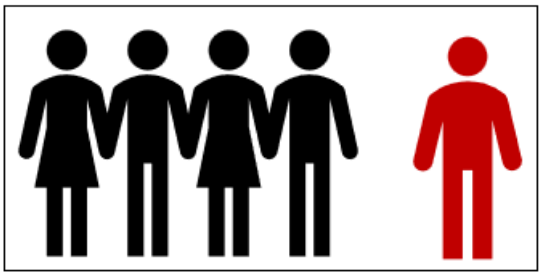
The widespread stigma attached to tuberculosis is one of the main causes of these deaths. As a social determinant of health, stigma is influenced and spread by interpersonal attitudes, institutional and community norms, and delayed care-seeking behaviour. It is pertinent to all stages of the tuberculosis treatment cascade.

A community-based survey conducted in 30 districts in India reported, 73% had a stigmatizing attitude toward TB patients.[4]

There is a report of more than 50% of TB patients experiencing stigma after being diagnosed[5]. Yet another study conducted in India, estimated that >200 000 patients experience pre-treatment loss to follow-up (PTLFU) annually in the national TB programme[6]. This speaks to the significant gap in tuberculosis care in India and around the world—that is, the patient dropout rate following diagnosis but before to treatment registration. These high rates of PTLFU have a number of causes, and stigma is one of them. Additionally, it has become clear that a major factor in the loss of tuberculosis patients to treatment is the unfavourable attitude of medical professionals and the absence of sufficient counselling[7]. It is concerning when medical professionals stigmatise TB patients because they look up to them to relieve their suffering from their sickness. This is a serious barrier to the eradication of tuberculosis and goes against the fundamentals of healthcare.

In light of this, it is concerning that the majority of TB control efforts have focused on biological strategies rather than paying enough attention to behavioural measures that lessen stigma.[8]

TB & Discrimination:



Discrimination is when someone behaves badly towards you.

TB discrimination manifests in various forms, including employment discrimination, where people with TB may face job loss, denial of employment opportunities, or stigma-related workplace harassment. In educational settings, TB patients may be denied admission, excluded from classes or activities, or experience stigma-related bullying. Healthcare discrimination can lead to delayed or denied diagnosis and treatment, poor quality of care, and inadequate pain management. Social services discrimination may result in denial of food assistance, inadequate housing, or limited access to transportation. TB stigma can also lead to human rights violations, including denial of the right to health, education, and social services. Furthermore, TB patients may experience stigma-related violence, economic discrimination, and social isolation, ultimately leading to delayed diagnosis, poor treatment adherence, increased transmission, and mental health impacts. Addressing TB discrimination requires policy change, education, community engagement, support groups, and empathy to protect the rights and dignity of TB patients.

Health Related Stigma & Discrimination:
Health-related stigma & discrimination refers to the negative attitudes, beliefs, and behaviours that society associates with certain health conditions, illnesses, or disabilities. This can lead to discrimination, marginalization, and social exclusion of individuals or groups affected by these conditions.

Types of Health-Related Stigma:
1) Internalized Stigma: Self-stigma or shame felt by individuals with a stigmatized condition.
2) Perceived Stigma: Fear of discrimination or judgment from others.
3) Enacted Stigma: Actual experiences of discrimination or mistreatment.
4) Courtesy Stigma: Stigma experienced by family members, caregivers, or associates of individuals with a stigmatized condition.

Factors Contributing to Health-Related Stigma:
1) Lack of Understanding: Misconceptions or ignorance about a condition.
2) Fear of Contagion: Belief that a condition is infectious or contagious.
3) Cultural or Social Norms: Societal values or norms that perpetuate stigma.
4) Media Representation: Negative or stereotypical portrayals in media.
5) Power Imbalances: Discrimination based on social, economic, or political status.

Stigma, Discrimination & Myths:
People with tuberculosis frequently experience discrimination, due to the stigma and misconceptions surrounding the illness.

It is not possible for tuberculosis to spread via sharing utensils or tableware. For you to have a chance of getting tuberculosis, you have to be exposed to airborne TB droplets for a minimum of eight hours. Thus, it is likewise untrue that tuberculosis may spread quickly on public transportation.[9]

Other some myths are-

1) Everyone with TB is infectious-
This is not accurate. A TB patient can only spread the infection if they show symptoms. This implies that TB cannot be spread by a person who has a latent infection. Only in cases when the bacteria are present in the throat or lungs can a person spread TB. A person is unlikely to spread the illness if the bacteria are present in other body areas like the kidney or spine. People with tuberculosis become non-infectious 2-3 weeks after beginning treatment.

2) TB is genetic-
Contrary to popular belief, tuberculosis does not spread from parent to child.

3) There is no cure for TB-
It's untrue; tuberculosis is curable. Isoniazid antibiotics are the most widely used treatment for latent tuberculosis infections. This medication should be used by TB patients as a single daily pill for 6-9 months.

For 6-12 months, doctors typically prescribe a mix of antibacterial drugs to patients who have an active illness. Isoniazid is frequently used with pyrazinamide, ethambutol, and rifampin.

10 medications have been licensed by the Food and Drug Administration (FDA) to treat tuberculosis (TB), according to the Centres for Disease Control and Prevention (CDC).

To treat multidrug-resistant tuberculosis, a patient may require at least six medications.

4) TB only affects people in low-income countries-

This is a myth; tuberculosis can strike anyone, anywhere in the world. On the other hand, tuberculosis is more common in other areas.

South East Asia accounted for 44% of all new cases of tuberculosis in 2019, according to the WHO. Two-thirds of new cases come from eight countries: South Africa, Bangladesh, Pakistan, Nigeria, Indonesia, China, the Philippines, and India.

However, 8,916 cases of tuberculosis were reported in the US in 2019. In 2018, 52,862 instances were reported in Europe.

5) TB spreads through shaking hands-

Given the seriousness of tuberculosis, people's concerns regarding its spread are understandable. Myths have emerged as a result of this.

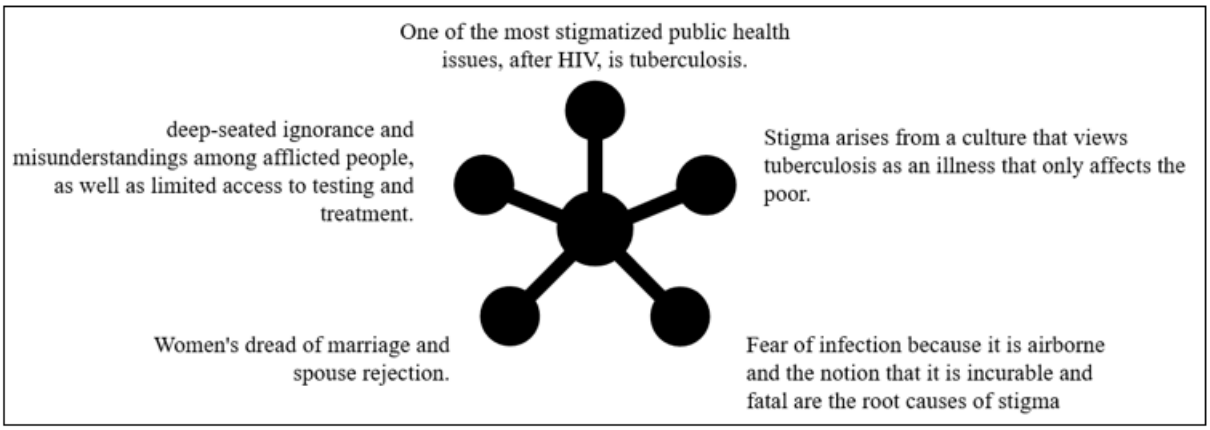
TB cannot proliferate by:

- Extending a handshake
- Sharing food or drinks, scuffing toilet seats or bed linens
- Toothbrush-sharing

Only when a person has an active infection in their throat or lungs coughs, sneezes, speaks, or sings may TB spread.

6) TB is always fatal-

Without treatment, tuberculosis (TB) can be fatal; however, modern medicine allows doctors to cure the infection effectively. [10]



In the community, TB patients experience stigma and discrimination in many ways.[11]

2. Challenges

During the past years, the TB burden has been slowly decreasing at a rate of 1.5–2% per year. Such low speed is due to many factors. Firstly, there is a large TB (latent) infection pool, which, together with risk factors for active disease, global ageing, slow and insufficient case detection, low cure rates and drug resistance, favours the slow incidence decline. Furthermore, TB is tightly linked to social-economic determinants. The main vulnerable people are those living in poor, crowded and poorly ventilated conditions; those living with HIV, diabetes, malnutrition, alcohol abuse, and drug and tobacco use; and migrants, refugees, prisoners, ethnic minorities and marginalised populations. The higher the gross domestic product (GDP) the lower the TB incidence, whilst the higher the level of undernutrition, the higher the incidence. Moreover, other major disruptive events like the current pandemic and political conflicts greatly slow down the decline of TB burden.[12]

3. Prevention & Control

Stigma has mostly stayed a low-priority issue in global efforts to prevent and manage tuberculosis. However, there has been a notable increase in knowledge of this element of tuberculosis care in recent years. The focus of efforts to control the stigma surrounding the illness is on interventions designed to lessen the stigma attached to tuberculosis. These interventions include increasing public awareness, counselling patients on emotional and problem-solving skills, creating media messages that are both culturally sensitive and scientifically sound, providing financial support to patients, and enhancing the qualities of healthcare professionals such as empathy, concern, respect for the patient, and cultural sensitivity.[13]

Government organisations and corporate partners have established a training curriculum plan in nations like India to eradicate the stigma and discrimination related to tuberculosis.[3]

4. Conclusion

TB stigma and discrimination remain pervasive and debilitating issues, perpetuating the TB epidemic and undermining efforts to control and eliminate the disease. This study highlights the complex interplay of factors contributing to TB stigma, including sociocultural beliefs, healthcare provider biases, and structural barriers. To effectively combat TB, it is essential to address these underlying factors and develop targeted interventions to reduce stigma and promote inclusive care. By prioritizing stigma reduction and discrimination elimination, we can improve health outcomes, enhance quality of life, and accelerate progress towards a TB-free world. Further research and programmatic efforts are needed to inform and scale up evidence-based stigma reduction strategies, ensuring that individuals affected by TB receive compassionate and comprehensive care, free from discrimination and stigma.

References

[1] Goffman E: Stigma: Notes on the Management of Spoiled Identity. Simon & Schuster, New York; 1963.
[2] Chen X, Du L, Wu R, et al.: Tuberculosis-related stigma and its determinants in Dalian, Northeast China: a cross-sectional study. BMC Public Health. 2021, 21:6. 10.1186/s12889-020-10055-2

[3] Training curriculum strategy to end stigma and discrimination associated with tuberculosis. (2022). Accessed: May 30, 2024: https://tbcindia.gov.in/WriteReadData/l892s/6076648734Stigma_Training_Manual.pdf.
[4] Sagili KD, Satyanarayana S, Chadha SS. Is knowledge regarding tuberculosis associated with stigmatising and discriminating attitudes of general population towards tuberculosis patients? Findings from a community-based survey in 30 Districts of India. PLoS One. 2016;11(2):1–11.
[5] Shivapujimath R, Rao AP, Nilima AR, et al. A cross-sectional study to assess the stigma associated with tuberculosis among tuberculosis patients in Udupi district, Karnataka. Indian J Tuberc [Internet]. 2017;64(4):323–326.
[6] Thomas BE, Subbaraman R, Sellappan S, et al. Pretreatment loss to follow-up of tuberculosis patients in Chennai, India: a cohort study with implications for health systems strengthening. BMC Infect Dis. 2018;18(1):1–11.
[7] Thomas BE, Suresh C, Lavanya J, et al. Understanding pretreatment loss to follow-up of tuberculosis patients: an explanatory qualitative study in Chennai, India. BMJ Glob Heal. 2020;5(2):1–13.
[8] Atre SR, Mistry NF. Multidrug-resistant tuberculosis (MDR-TB) in India: an attempt to link biosocial determinants. J Public Health Policy. 2005;26(1):96–114.
[9] Stigma and myths [Internet]. TB Alert. https://www.tbalert.org/about-tb/global-tb-challenges/stigma-myths/
[10] 6 myths about tuberculosis [Internet]. www.medicalnewstoday.com. 2021. https://www.medicalnewstoday.com/articles/medical-myths-all-about-tuberculosis
[11] Stigma and Discrimination towards TB Patient | Knowledge Base [Internet]. Ntep.in. 2019. Available from: https://ntep.in/node/689/CP-stigma-and-discrimination-towards-tb-patient
[12] World Health Organization (WHO). Global Tuberculosis Report 2022. Geneva, WHO, 2022. www.who.int/publications/i/item/9789240061729
[13] Yadav S (June 08, 2024) Stigma in Tuberculosis: Time to Act on an Important and Largely Unaddressed Issue. Cureus 16(6): e61964. doi:10.7759/cureus.61964