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RESEARCH ARTICLE

TUBERCULOSIS RELATED STIGMA AND DISCRIMINATION IN INDIA

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Abstract

Every year, 10 million people fall ill with tuberculosis (TB). Despite being a preventable and curable disease, 1.5 million people die from TB each year – making it the world’s top infectious killer. TB is the leading cause of death of people with HIV and also a major contributor to antimicrobial resistance. Most of the people who fall ill with TB live in low- and middle-income countries, but TB is present all over the world. About half of all people with TB can be found in 8 countries: Bangladesh, China, India, Indonesia, Nigeria, Pakistan, Philippines and South Africa. About a quarter of the global population is estimated to have been infected with TB bacteria, but most people will not go on to develop TB disease and some will clear the infection. Those who are infected but not (yet) ill with the disease cannot transmit it. People infected with TB bacteria have a 5–10% lifetime risk of falling ill with TB. Those with compromised immune systems, such as people living with HIV, malnutrition or diabetes, or people who use tobacco, have a higher risk of falling ill.

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Introduction:-

In India, TB is still one of the most commonly prevalent diseases as far as both morbidity and mortality is concerned. The incidence is quite high but it is only the tip of the iceberg. There are many missed cases either due to non-reporting by private sector or due to misdiagnosis. The next issue is inadequate and improper treatment of identified cases leading to increasing burden of drug resistant TB. Availability and affordability of sound diagnostic technology which helps in early diagnosis of TB cases (both non -DR-TB and DR-TB cases) is missing from many parts of country. TB has a tremendous effect at individual, family and community level. This way it even affects the economy of a country. It is still neglected as India is more concentrating towards other conditions like Non-Communicable Diseases and other emerging health issues.

In spite of newer modalities for diagnosis and treatment of TB, unfortunately, millions of people are still suffering and dying from this disease. TB is one of the top three infectious killing diseases in the world: HIV/AIDS kills 3 million people each year, TB kills 2 million and malaria kills 1 million. Even though tubercle bacilli was identified nearly 130 years ago, a definitive understanding of pathogenesis of this disease is still deficient. Although it can affect people of any age, individuals with weakened immune systems, e.g., with HIV infection, are at increased risk. Since the immune system in healthy people walls off the causative bacteria, TB infection in healthy people is often asymptomatic.

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Stigma related to Tuberculosis

In some cultures, TB is associated with witchcraft. TB can be considered a ‘curse’ on a family, as the illness often affects multiple generations – we know that this is simply because TB is an airborne illness, which is more likely to be spread among people living in close proximity.

TB is often associated with factors that can themselves create stigma: HIV, poverty, drug and alcohol misuse, homelessness, a history of prison and refugee status.

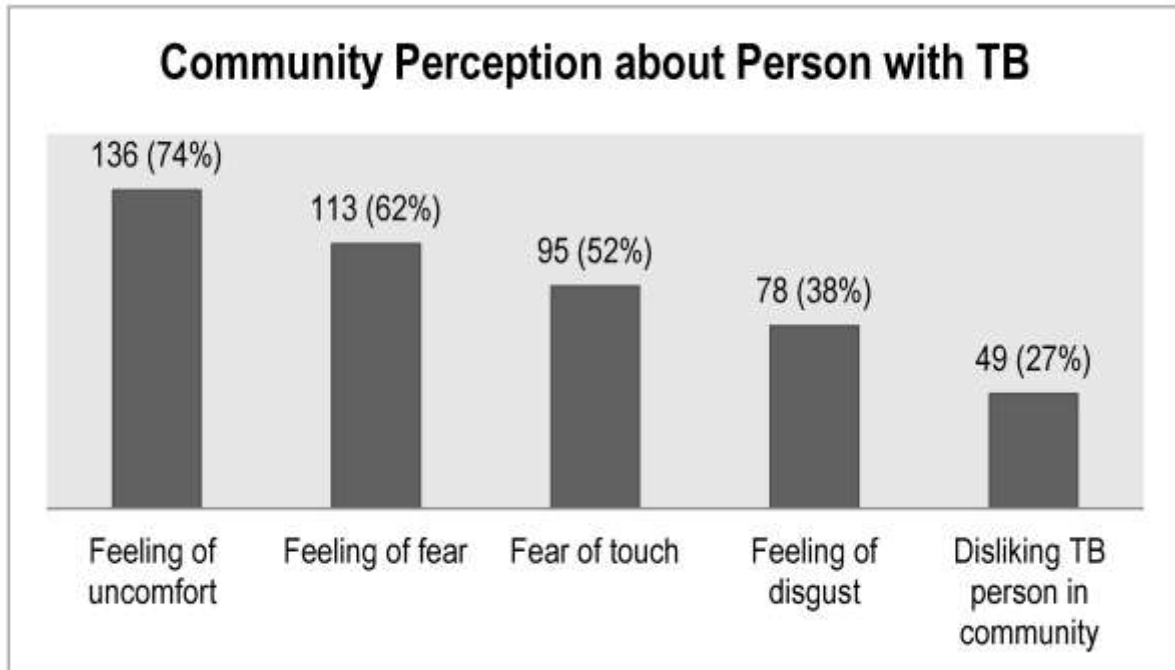
People who are discriminated against may be isolated socially, particularly in small communities – even entire families may be shunned. Women are often blamed as the source of TB, and those affected by the illness may be divorced or considered unworthy of marriage.

TB-infected individuals perceive themselves to be at risk for a number of stigma-related social and economic consequences. Because the most common result of TB stigma is isolation from other members of the community, TB infection can substantially impact economic opportunities. For example, the stigmatization of TB in Ghana has led to the prohibition of TB-infected individuals from selling goods in public markets and attending community events. When an individual dies of TB, fear of TB stigma can lead families to hide the cause of death from other members of the community, even when such information might be useful in targeted TB screening. Similarly, fear of TB stigma can lead infected individuals to hide their TB status from their families. TB stigma also results in a sense of shame or guilt, leading to self-isolation as TB-infected individuals internalize their community's negative judgments about the disease.

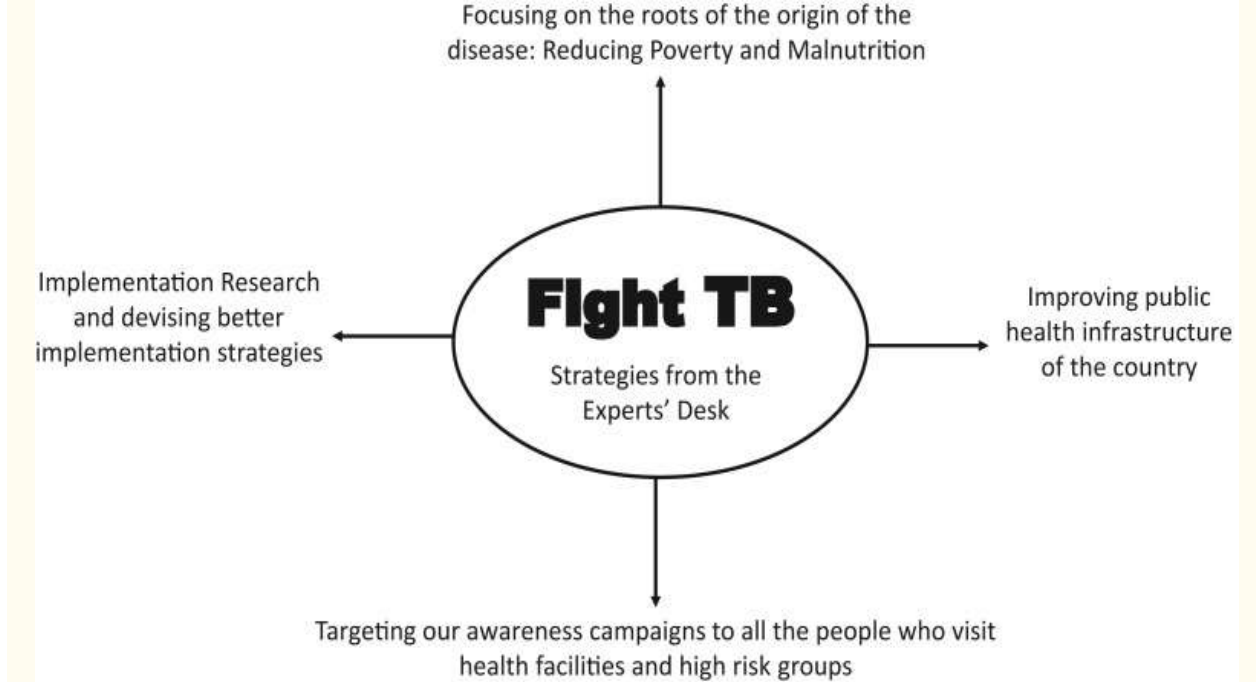
The socioeconomic consequences of TB stigma differ in men and women. In general, men are more concerned with the impact of TB stigma on their economic prospects, which include job loss and reduced income. While TB stigma also affects their financial status, women tend to be more concerned that TB stigma will adversely impact their marriage prospects or that their families will shun them. In some areas, however, men are more worried than women about the effect of TB stigma on their marriage opportunities. Married women with children may fear that their husbands will reject them if they are diagnosed with TB and that they will be unable to care for their families.

Stigmatization is a social determinant of health. Stigma occurs because of community and institutional norms about undesirable or disvalued behaviors or characteristics. When diseases are stigmatized, the fear of the social and economic consequences following diagnosis can make individuals reluctant to seek and complete medical care. The structure of a community's beliefs and norms about a disease and the resulting stigma can, therefore, substantially impact health. In this article, we systematically reviewed the literature on TB stigma, including studies that characterized and measured TB stigma; assessed its impact on TB diagnosis and treatment; and explored interventions to reduce TB stigma.

The most common cause of TB stigma is the perceived risk of transmission from TB-infected individuals to susceptible community members. Depending on geographic region, however, TB is also stigmatized because of its associations with HIV, poverty, low social class, malnutrition, or disreputable behavior. TB stigma has a more significant impact on women and poor or less-educated community members, which is especially concerning given that these groups are often at higher risk for health disparities. TB stigma may, therefore, worsen preexisting gender- and class-based health disparities.



TB services in both public and private healthcare sectors.



The impact of stigma

Fear of discrimination can mean people with TB symptoms delay seeking help, making it much more likely that they will become seriously ill and infect others. This then perpetuates the myth that it is the TB treatment itself that causes deaths, as treatment is much less effective if left until the illness is in its advanced stages.

Stigma around TB can also make people reluctant to stick with their course of treatment – over the many months this takes – for fear of being ‘found out’. By taking treatment irregularly, people risk developing drug resistance.

Myth busting

TB is not spread through spitting or sharing crockery or cutlery. You need to be exposed to TB droplets in the air for a long period of time – typically eight hours or more – to be at risk of contracting the illness. This means the idea that TB is easily spread on public transport is also a myth.

Conclusion:-

Government of India is making lot of efforts to bring down the problems associated with TB through revised plans and their implementation across the country. In spite of this, there is a long way to go to achieve significant reduction in high incidence and prevalence of TB in India. Factors like lack of awareness and resources, poor infrastructure, increasing drug resistant cases (MDR TB and XDR TB), poor notification and overall negligence are the major challenges. Contagious disease like TB can victimize anyone. Even vaccinations do little to reduce its impact. If we eradicate poverty and undernourishment, educate the masses and eliminate the stigma attached with TB, we can hope for a disease-free future. The current Coronavirus pandemic in 2020 has also given us excellent opportunity to create awareness about TB in the community at various levels.

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