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## Stigma and discrimination of tuberculosis in India: A systematic review

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### Abstract

**Background:** Tuberculosis remains a major public health issue in India, with the country responsible for 1 in 5 of all confirmed TB cases worldwide. Tuberculosis and other communicable diseases such as human immunodeficiency virus/acquired immune deficiency syndrome, leprosy, etc. have been associated by society for decades with stigma and discrimination; this may interfere with the lifestyle and management of disease among these patients.

**Objective:** To perform a systematic literature review to assess the scenario of stigma, discrimination, and elimination of TB in India.

**Methods:** The literature search was carried out using databases like PubMed, Cochrane, Web of Science and Google Scholar. The results were correlated and analysis was performed.

**Results:** The studies projected various aspects of discrimination and stigma faced by TB patients. Further, detailed results will be discussed during the conference.

**Conclusion:** Positive therapy interventions are recommended for advancing age and education patients with tuberculosis that can help reduce stigma and improve the quality of life.

**Keywords:** Tuberculosis, stigma, discrimination, elimination, and review

### Introduction

In India, tuberculosis is one of the major public health burdens, recorded among 1.98 million incident cases in 2009, whereas in 2016, it is increased by about 3.6 million incident cases. From 2009 to 2016 they were the doubled amount of incident cases were recorded. The burden of tuberculosis is high when comparing another communicable disease (Thomas *et al.*, 2016a) [9]. The Revised National Tuberculosis Control Program is now developed and eliminate Tuberculosis in the country to make Zero Expenditure, named as National Elimination of Tuberculosis Program-2025 (NTEP). The Multidrug-resistant (MDR-TB) is another burden regarding TB, where the new cases are developed, the continuous treatment protocol is taken under the directly observed treatment scheme (DOTS) for 6 months, but some patients become resistant over the Rifampicin and other drugs (Philip *et al.*, 2015a) [6]. The increases of incident cases from one decade to the MDR-TB also increases, in this case, some patient becomes crucial condition. The Mortality Rate of TB also increases vice-versa. The Tuberculosis missing Cases is high when compared to India's burden and the Global Burden, Early detection of TB is a major Elimination and discrimination process.

The case notification, Mobilisation, Case detection are the important factors, where finding the Missing cases. However, the lack of public awareness, coupled with the involvement and engagement of communities and non-governmental organizations have identified the challenges among the progress towards Tuberculosis. Numerous communicable diseases are involved in the stigma and segregation, for example, HIV/Acquired immunodeficiency syndrome (AIDS) and leprosy (Kamineni *et al.*, 2011) [3]. The effects are involved in the field, like home, working environment, School, colleges, and especially on Community, discrimination occurs and they become more suffering among the others. The effect on the treatment procedure and the lack of awareness are eliminating over the others, then the stigma and discrimination sustained from the country. The treatment protocol and the knowledge of the Public and the household's members involved in the way to eliminate the discrimination. The study reviewed various studies to evaluate the stigma and discrimination in India.

## Objective

To perform a systematic review to access the scenario of Stigma, Discrimination and Elimination TB in India.

## Methods

The Systematic review is conducted according to Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines and Cochrane protocols.

## Search strategy/criteria

Using the terms “Tuberculosis”, “Stigma”, “Discrimination”, “Elimination” and “Review”, we searched PubMed, Cochrane, Web of Science and Google Scholar for published articles addressing Tb stigma and discrimination. Zotero, a free and open-source Reference Management software to cite and manage the data by online library program.

## Selection studies

We retrieved using the search keywords out of 14 articles. We reviewed each article; the selection was done using the following inclusion and exclusion criteria (Thomas *et al.*, 2016a) [9].

## Interpretation

Globally, India has the highest TB burden, nearly 23% of the global incidence of the new cases, every year. According to the WHO report nearly 2.2 million deaths occurring every year. Since we referred the 14 articles based on the stigma and discrimination of TB patients using the keywords of ‘Stigma’ ‘Discrimination’ ‘Elimination’ and ‘Review’, the study has been conducted almost all over India to determine the factors that associated with TB stigma and discrimination by both Qualitative and Quantitative Method by using validated scales and in-depth interviews to the patients (Chin *et al.*, 2000).

Stigma being a constant barrier for both physically and mentally to ending the TB treatment, many challenges had been faced by MDR-TB patients due to disease and treatment complexities by psychologically (Sagili *et al.*, 2016a) [6,7]. Migrant and caste are the major cause of stigma and discrimination among patients to continue treatment. In the high rates of stigma and discrimination ‘socioeconomic status’ plays a vital part in threatening reason among infected patients, family members and also in the community because the poor level of health education was observed and identified. Since the lack of awareness about the disease impacts and shows negative results in the National health programmes. According to the recent survey in Odisha based on the Rapid Assessment and Response by complementary Qualitative and Quantitative evaluation found an approach for TB related health problems, risk behaviours, and social consequence (van Brakel *et al.*, 2019a) [10]. The rapid assessment gave a quality key recommendation for the stakeholder’s considerations for the greater Cost-efficiencies and continuous improvement in the ACSM program in the upcoming years with a period of 3-5 years. In the future for the improvement of the National TB Control Program and the reduction of TB, some medication in the DOTS strategy and the intervention of additional programs should be initiated. Since the expectation and stigma rates being equal in the TB elimination in India, stigma reduction therapy should be designed to improve the adherence of DOTS to increase the TB elimination rate

across India. To address the psychological challenges by MDR-TB, economic intervention suggest improvement in treatment adherence and cure rates among TB patients. We observed education is the major cause for ‘Discrimination’ among poor community people, to stabilize this result health education and awareness about health issue should be in high rates by the health workers, ASHA worker, or medical campus and even by the NGO in the affected community across all over India. Social support is an essential part of TB patients to come out of the illness and a faster recovery period. In the private sector, the specialist should address important stakeholders in the TB notified community (Shivapujimath *et al.*, 2017) [8]. Communication and trust-building are the major key factors for the behavioural challenges among TB patients both physically and mentally in the private sector for the better recovery phase during the patient’s treatment time. Based on the patient’s expectation criteria good infrastructure of health facility also being an essential part of the stigma and discrimination of TB being observed and noted, the public-private partnership should have emerged for the increased elimination rate of TB across India (Kumar, 2016) [4, 6]. Policy changes and soft skill training also can be initiated among the health workers for the Public-private partnership for the coordination of the health workers towards the ‘Goal of Elimination of TB across India’.

## Discussions

The researchers have an idea of implementations for Informing the health policy decision-makers about the transmission of TB and attaching the interpretation of their TB illness and stigma to it, research on health-related stigma, expanding structural stigma reduction interventions (van Brakel *et al.*, 2019b) [10]. To influence adherence to DOTS scheduled caste plays an important factor, migration and knowledge about TB also considered as one of the significant impact factors. In the context of stigma conducting in-depth qualitative studies may help to get more insights into the cause of exclusions from DOTS (van Brakel *et al.*, 2019a) [10]. Most of the participants reported that fear of transmission of TB has led to isolation and discrimination of the patients. Cultural and social changes have let to the transition of food patterns, cultural beliefs, marriage practices, and occupations people in the community have a belief that this factor had increased the emergence of communicable diseases (Deshmukh *et al.*, 2016) [1]. By doing FGDs researchers found that the main impediments to successful patient outcome to be limited access to diagnosing centres and less number of treatment facilities people need to be aware of the early diagnosis and correct treatment needs to be informed so that people tend to seek health facility the health care providers should have knowledge about the people’s cultural barriers accordingly to the population. Due to the side effects of the drug people couldn’t work efficiently as before therefore loss of income is also a major impediment leading to treatment default, economic and financial challenges have a psychological impact on MDR patients and their family’s researchers have also reported alcohol abuse as one of the risk factors for MDR-TB. Psychosocial problems for HIV/MDR patients are particularly challenging, there is an unusually high in mortality rate due to MDR-TB among the HIV infected patients, future studies need to look on whether the psychosocial intervention has an impact on long term

treatment outcomes (Thomas *et al.*, 2016b) <sup>[9]</sup>. The qualitative study suggested that student's stigmatization on patients is based on social factors like lack of formal education, low economic status, and rural background. Disclosure of the illness to the patient's family members is another dilemma for the health professional in the case of a stigmatizing illness. Researchers advise that inclusion of the topic "Handling stigma in illness – the role of the health professional" in the medical and nursing curriculum for undergraduate students. The male vignette counters a cultural stereotype that women with TB face more kind of marital problems researchers found that strong family bond and community support can cause a positive implication for stigma reduction (Philip *et al.*, 2015b) <sup>[6]</sup>. Differentiating reasonable modes of preventing the spread of TB by recognizing culturally salient features of stigma such as the concern about the ability to arrange marriage are relevant for public health interventions awareness of the local stigma as reported indicates the values of social and cultural research for TB control. Most respondents said that they isolated themselves from their family and friends to avoid infecting them. Discrimination against people with TB by individuals unconnected with the patients they are fearful of the perceived risk of infection perceived links in-between TB and other causes of discrimination particularly poverty and low caste, perceptions that TB was a divine curse sent down to punish former unacceptable behaviour. One of the studies revealed that age and educational status influenced stigmatization among TB patients. Improvising the awareness regarding the impact of adequate treatment and follow up can bring a change inpatient and community and DOTS and community workers may help discharge these duties to improvise the awareness of the family and social support of TB patients (Pai *et al.*, 2016) <sup>[5]</sup>. Researchers observed that people who have awareness about that TB was curable had stigmatizing attitudes significantly higher than those who did not know this. There is an urgent need to include social aspects in our TB program. Improvement of the interpersonal skills of the health providers participating in the DOTS program was recommended in relation to the utilization of TB care in India. Consistent motivational and attitudinal building for persons involved in health care services to ensure compliance in a public health measure like notification. There is no concrete and comprehensive communication strategy existing in RNTCP for de-stigmatizing the community. Stigma reduction strategies will be helpful which takes special care in areas like caste, joint families and urban-rural differences. Studies in some regions where TB stigma is high should be conducted to estimate the impacts of TB clubs, counselling, etc. men frequently reported that concerns about maintaining a sexual life with their wife appear to have largely fuelled by their doctor's recommendations to refrain from sex. Some men reported that their wives had refused to have sex it is unclear to which extent this can do with stigma and avoidance (Kamineni *et al.*, 2011) <sup>[3]</sup>. The healthcare provider should clearly explain the duration of infectivity, and also to be sensitive to the financial impact of limiting work and the importance of male gender roles as financial providers. Sensitization activities generally improved IPC skills, community involvement and social mobilization in TB control activities. The strategic use of tailored messages to address specific TB problems in some low performing areas has led to more positive behavioural outcomes which are

mostly related to the TB challenges encountered in those areas, which has also improved efficiencies in service delivery in some constrained settings. to assess specific interventions and problem issues, conduct succession planning to ensure future sustainability, maintain gains achieved to date, and momentum of Project in problem districts, and last, develop public health priorities for Advocacy, Communication, and Social Mobilisation to optimize the delivery of all state health priorities (Sagili *et al.*, 2016b) <sup>[6,7]</sup>.

## Results

Compared to Urban Area, Rural Area was found with High level "Stigma". Rather the high-level stigma people, lower level stigma people stay close to Dots. People hide Tuberculosis majorly because they think the person might be isolated from the family, so they search for PHCs and get temporary treatment. Commonly people have a particular idea that HIV, CANCER, and AIDS will accompany Tuberculosis. They should have a Prior test when they have severe cough and sputum through Labs. Lack of Hope, Isolation, and Fear are major expressed feelings. Patients go through the Depression at the base, Quality of life and mental health must be focused highly. The relationship between a doctor and a person (Illiterate) should have the same focus on each other (Joseph *et al.*, 2019) <sup>[2]</sup>. The gender varies exist in the Community of TB and Stigma, Both the Male and Female worries on their Remoteness by Family-Workers and Neighbours. The main cause for the stigma is considerable discrimination and TB spreads through AIR (when an infected person coughs or sneezes). As a result of discrimination, the patients felt that they are biased by other healthy people. About at the initial stage, 81% of people believed that TB will be cured but 18.7% of people discontinued the treatment because of Discrimination. As referred high-income groups have a twice higher chance of having stigmatizing compared to the low-income group. SDA responds to individual TB knowledge indicators. Influencers of stigma have become strong. Stigma Indicators among males and females have several differences. Predominantly both the gender feels embarrassed (Shivapujimath *et al.*, 2017) <sup>[8]</sup>. Although, Impact of TB is on Sexual relationship and social activity. Consequently, this is the shaping of Stigma and Discrimination of TB.

## Conclusion

We conclude the study with the Review of Study in India about Stigma and Discrimination, we excluded the other countries. Stigma is a high level among the rural area than in the Urban, especially in the Tribal people, the discrimination Rate is high and the Sufferings are much more. Because of the sufferings, the patient affects along with the psychosocial conditions and other Psychological disturbance. The Employment status is poor when the patient attains the Stigma and the Neighbourhoods, community, other Social Contacts are playing an important role in changing their Day to day life. The patient stigma is an offense and easily kills the nation, if we eliminate the Tuberculosis, then we eliminate the stigma among the door to doorstep action, the motto of the government to eliminate the Tuberculosis is important and the major Factor for the Program- NTEP-2025. The nation builds with their individual and their Community also.

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