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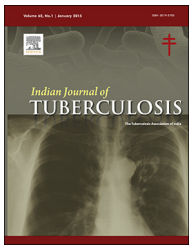

Original article

Tuberculosis related stigma and its effect on the delay for sputum examination under the Revised National Tuberculosis Control Program in India

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ABSTRACT

Background: One major barrier to achieve goal of tuberculosis (TB) control program globally, is the stigma attached to the disease. Perceived stigma can delay sputum test in time. Delay will lead to spread of infection in the community. There is no scientific information available in India exactly looking into the association between delay in sputum examination and stigma.
Aim: We conducted a study in rural West Bengal among persons with cough for 2 weeks or more to assess their level of stigma, its influence on delay for sputum test and identify factors those shape the level of stigma.
Methods: A community based cross sectional survey was conducted from February to June 2015 in West Bengal, India. We interviewed 135 persons of 15–60 years. Data were collected using a pretested structured questionnaire. Chi-square and logistic regression analysis were done using SPSS 23.0 statistical software.
Results: Among the 'lower stigma' group (score 4–24), 'delay' (14–25 days) is found among 46.2% respondents and 'much delay' (26–120 days) among 53.8%. Among the 'higher stigma' (score 25–36) group, 'delay' is found among 20.5% respondents and 'much delay' among 79.5%. Persons with lower stigma are 0.17 times likely to delay than persons with higher stigma [adjusted odds ratio (AOR): 0.17 (0.044–0.668), $p = 0.011$)]. Important influencers of stigma are caste [AOR: 5.90 (1.66–20.90), $p = 0.006$], number of family members [AOR: 3.46 (1.08–11.06), $p = 0.009$] and residence in urban or rural [AOR: 3.97 (1.03–15.27), $p = 0.045$].
Conclusion: Revised National Tuberculosis Control Program in India should de-stigmatize the community giving priorities to lower castes, big families and rural areas.

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1. Introduction

Population of India is second highest in the world and whereas, annually 25% of the global burden of tuberculosis (TB) incidences is from India which comes around 2.2 millions in 2015. TB incidence per 100,000 population has declined to 167 in 2016 from 216 in 1990.[1,2] According to the Revised National Tuberculosis Control Program (RNTCP), the control of TB lies mostly at three levels: (i) TB suspects are referred to the sputum testing facility under RNTCP, (ii) diagnosed cases are put on treatment and (iii) those who are put on treatment, they remain adherent.[3] First and foremost important step is that TB suspects are referred to the facility for sputum test, otherwise they continue to spread infections.[3] TB suspect referral in India is 157 per 0.1 million population compared to 151 per 0.1 million population in West Bengal, when the expected rate is 203 per 0.1 million.[4–6] As per the RNTCP guidelines, a person with cough for two weeks or more should do sputum examination to diagnose whether TB infection has occurred to avoid further spread of the infection within the community.[3] Around 26.3% patients did not turn out to facilities for sputum examination after having cough for many days in Bangladesh.[7] However, it is found that various caste and vulnerable groups lack the knowledge about TB and its services.[8] To comply with the objective of RNTCP fully; the program has to mobilize community to public facilities for sputum test as first and foremost strategy.[9] RNTCP which is implemented through public health system is yet to pay adequate attention to social, psycho-social, cultural and political factors that make TB endemic among poor and excluded population. Many socially excluded patients are at risk of delayed presentation, poor adherence, and loss to follow up.[10,11] Among many factors those influence delay in presenting them to facility for sputum examination for diagnosis of TB; factors like caste, poverty, residence (urban or rural), accessibility and knowledge about TB and psycho-social issues are important. One of the most important barriers is stigma attached to TB which remains very much under-researched in the context of India. Association between delay in seeking diagnostic sputum examination services and level of stigma is highly significant (odds ratio (OR): 5.9 and $p = 0.01$).[12] Stigma is a deeply rooted socio-cultural vague concept and cannot be easily assessed. TB stigma is an under researched area. Studies in diverse contexts are needed so that stigma will be considered as a priority in the organization of care for people affected by TB.[13] Stigma associated with TB has been identified as a major barrier to health care access and to quality of life in TB management.[14] One of the most important barriers to achieve success in TB control program globally is the stigma attached to TB in most societies. Because of fear of infection, most of the community members want to isolate the infected person from social functions, crowd or even with restriction within the household if the infected person belongs to the family.[15] But there is very little information available from Indian context on how stigma influences access to sputum examination services. Research will be relevant to find out level of stigma, effects of stigma in delay of seeking sputum examination services and influencers of stigma in the context of TB diagnosis. This research study aims to explore the level of stigma perceived by people about TB, influence of stigma in the delay of diagnosis by sputum examination and different influencers those shape the form and extent of stigma.

2. Methods

2.1. Study design and setting

We have conducted a cross sectional epidemiological study. In West Bengal there are 20 districts having 3 subdivisions – Jalpaiguri, Presidency and Bardhaman. From each sub-division, one district has been randomly selected. Thus, Birbhum, Jalpaiguri and North 24 Parganas have been selected those geo-ethnographically represent the state. As per RNTCP one Tuberculosis Unit (TU) caters 0.5 million population and one Designated Microscopy Centre (DMC) caters 0.1 million population. From each district 4 TUs have been selected using stratified sampling technique. From each TU, 3 DMCs have been selected using same technique. Thus total 36 DMCs have been selected. One DOT provider has been selected randomly from each DMC.

2.2. Sample size

Taking 26.3% as proportion of delayed access for sputum examination,[12] sample size has been calculated to be 111 [$n = (1.96)^2 \times 0.26 \times (1–0.26)/(0.10)^2 \times 1.5 = 111$] at 95% confidence limit, allowable error 10% and design effect 1.5. We have got 135 persons with cough for two weeks or more in our study as respondents.

2.3. Selection of respondent

From the selected DOT provider of the respective DMC, we have requested them to take to 3–4 persons with cough for two weeks or more. Thus we interviewed 135 such respondents. We included respondents of the group from 16 to 60 years, with cough for two weeks or more but and given consent for the study. We excluded them who have not done sputum examination test anywhere else.

2.4. Data collection

Stigma has been assessed based on 9 question items adopted as per the tool of Moya used in 2010. Cronbach's alphas for the scales were 0.911 for the community perspectives toward TB scale.[14] It has 1–4 options as per Likert scale. For 1, the respondent has strong disagreement; for 2, the respondent has disagreement; for 3, the respondent has agreement and for 4, the respondent has strong agreement. The tool and the statements for stigma measurement has been field tested and changed as per feedback received.

2.5. Statistical analysis

We have used profile of the participants and their stigma level as two important research variables in our study. Out of

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