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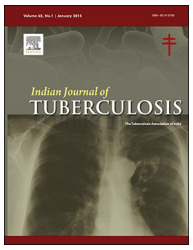

Original Article

A cross-sectional study to assess the stigma associated with tuberculosis among tuberculosis patients in Udupi district, Karnataka

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ABSTRACT

Background: For decades, tuberculosis and other communicable diseases like human immunodeficiency virus/acquired immune deficiency syndrome, leprosy, etc., have been associated with stigma and discrimination by the society; this can interfere with the lifestyle and disease management among these patients.

Objective: To assess the stigma experienced by tuberculosis patients and to find the factors associated with stigma.

Methods: A cross-sectional study was conducted among 209 sputum-positive and sputum-negative tuberculosis patients. Convenient sampling was used to identify the patients. A predesigned, pretested proforma from Explanatory Model Interview Catalogue developed by World Health Organization was used for data collection.

Results: The study revealed that out of 209 respondents, 51.2% of the respondents experienced some form of stigma. Majority of the patients have received only primary education and 71.3% of the respondents were males. Most of the patients were under category 1 of Directly Observed Treatment Short course. Age, education, and smear status of the patient were found to be associated with stigmatization ($P < 0.05$), whereas factors like gender, income, occupation, family history, and marital status were found to be not significantly associated with stigmatization.

Conclusion: Effective counseling measures are recommended for tuberculosis patients with advancing age and education which can help reduce stigmatization and thereby improve quality of life.

1. Introduction

One of the top 10 causes of global mortality is tuberculosis (TB).[1] Approximately one-fourth of the population is infected with the TB bacillus, and in the year 2014, 9.8 million people developed the disease and 1.5 million people died due to it worldwide.[2] In 2014, an estimated 1 million children became ill with TB and 140,000 children died of TB.[3] The situation has improved over the past two decades for the people with only

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TB disease, whereas the situation has worsened for others over the past two decades owing to the human immunodeficiency virus/acquired immune-deficiency syndrome epidemic.[1] TB is a leading killer of human immunodeficiency virus (HIV)-positive people; in 2015, 1 in 3 deaths among HIV patients was due to TB.[2] Globally in 2014, an estimated 480,000 people developed multidrug-resistant TB (MDR-TB), with the emergence of multidrug resistance in almost all the parts of India, following deterioration of the health infrastructure. The World Health Organization statistics for 2014 give an estimated incidence figure of 2.2 million cases of TB for India out of a global incidence of 9 million.[2] In 2014, a total of 43,689 people were diagnosed for smear-positive TB out of 61,328 people who were registered for treatment.[3] Mortality and morbidity rates are always high with TB, although it is almost curable with uninterrupted and appropriate treatment.[4] Most specialists recognize the integral part of patient adherence in endeavors to control the disease. Health-seeking behavior and knowledge about the causes of TB among groups and individuals are critical, and may influence the transmission of the disease.[5] There are beliefs and practices that may delay diagnosis, and in this way increasing the risk of spread of disease in the society.[1]

Numerous communicable diseases, for example, TB, HIV/acquired immune deficiency syndrome (AIDS), and leprosy, are connected with stigma and segregation, which enormously affect the sufferers.[4] The effect is felt at home, in the work environment, and in the community. Discrimination has critical contemplations for the arrangement of well-being and clinical practice. It adds to torment in different ways, and may defer care-seeking behavior and treatment, prompting delayed transmission of communicable illness, drug resistance, or intricacies that expand treatment costs for a treatable health issue.[5] Regardless of the presence of an effective cure for TB, TB rate in high-burden nations suggests obstructions to successful determination, treatment, and cure.[6] Evidence proposes that sociocultural variables and TB-related stigma may restrain patients from looking for care or finishing a full course of treatment, increasing morbidity and mortality because of TB, and aggravating its spread inside groups.[7]

The social stigma is perceived as a critical boundary for fruitful consideration of individuals affected by TB. TB has been and is still considered as a 'messy infection,' 'a capital punishment,' or as influencing 'liable individuals'.[8–10]

2. Methods

A cross-sectional study was conducted in Udupi district of Karnataka state between January and June 2016. All the patients registered under Directly Observed Treatment Short course (DOTS) for anti-TB treatment in all the three Taluks of Udupi district were included in the study. Patients who were not willing to participate, critically ill, and transferred out cases were excluded. The semi-structured interview schedule was adopted from Explanatory Model Interview Catalogue (EMIC) developed by WHO/Special Programme for Research and Training in Tropical Diseases as a research instrument. Pretesting and validation of the tool was done among 20 patients under anti-TB treatment. Twelve of the patients were found to be stigmatized among the total. The interview schedule consisted of sociodemographic profile, review of record, illness experience-related questions, and stigma-related questionnaire. The stigma-related questionnaire consisted of 22 items. Responses were coded on a 0–3 ordinal scale (0 = no, 1 = uncertain, 2 = possibly and 3 = yes). Items were scored on a 4 point Likert scale (3–0 with 3 = yes, 2 = possibly, 1 = uncertain and 0 = no). Maximum obtainable score was 66 and minimum score was 0. The participants scoring 33 and above were considered as stigmatized, and the participants scoring below 33 were considered as not stigmatized. Total patients registered under DOTS for the last quarter of 2015–2016 were 376. At 43% prevalence rate of stigma, and 95% confidence interval, and 80% power, the sample size was taken as 377. After obtaining the ethical clearance from the Institutional Ethical Committee (IEC 836/2015) and permission from the Joint Director of state TB cell and District Tuberculosis Control Officer (DTO), in the presence of Senior Treatment Supervisor (STS), after obtaining the informed consent, interview was conducted as per convenience of the STS by visiting the houses of TB patients.

Data were analyzed using Statistical Package for the Social Sciences (SPSS) 15 for windows (SPSS Inc., Chicago, IL). Statistical test of significance (Chi-square test) was used to find out the association between stigmatization and various clinical and sociodemographic variables.

3. Results

Among the 209 respondents, majority of the TB patients (24.40%) were found in the age group of 38–47 years while 18.18% were found in the age group of 28–37 years. Most of the TB patients have received only primary education (26.3%). Most of the participants were found to be males (71.3%), and nearly 29.7% of the TB patients were daily wage workers. Treatment pattern of the TB patients is shown in Table 1. More than 50% of the respondents had a family income of Rupees 5000–10000 per month.

Out of the 209 respondents, 51.2% of the respondents were stigmatized. Among 149 males, 76 (51%) of them reported that they were stigmatized, and out of 60 females, 31 (51.7%) of them reported; however, they were stigmatized and there was no significant association between gender and stigma experienced ($P = 0.931$).

About 81% of the respondents opined that TB will be cured, before the start of the treatment, and 92% of them said it is curable, after the start of the treatment. About 84.7% of them said that their friends were supportive if the disease status was not disclosed, while 84.7% of them said that their neighbors were supportive after disclosing the disease status. Majority (88%) of the participants reported that they were not invited for any social functions, and 98.08% of them were not attending any social functions.

In this study, it was found that 18.7% of the patients stopped/discontinued treatment. The most common reason they opined was loss of respect or being put to shame by the surrounding community. There was significant association between stigmatization and age ($P = 0.011$), education ($P = 0.007$), and smear status ($P = 0.045$).

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