

Challenges faced by patients while undertaking treatment for Tuberculosis

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ABSTRACT

Despite the immunisation of 92% of the Indian population against tuberculosis with the bacille Calmette-Guerin vaccine, India recorded 79,000 deaths due to this bacterial infection. Professionals in the field have tried to find the reason behind both, the high mortality and high infection rate in the country with the aim of eliminating tuberculosis in India by 2025 as part of the TB National Strategic Plan. A significant reason identified for this phenomenon is non-adherence to treatment due to challenges faced by the patients while undertaking treatment. The aim of the present research study is to identify the challenges faced by Indian tuberculosis patients visiting a dispensary in South Delhi undertaking treatment for tuberculosis and evaluating their relative importance in influencing their treatment experience through a mixed-method approach. Financial difficulties/loss of job/ school was found to have the highest mean rating which mirrors the trend in other developing countries such as Bangladesh. The study has implications for the government at different levels and private hospitals can be convinced that providing free-of-cost treatment is not enough and more budget should be allocated to tuberculosis treatment to ensure that patients receive a wholesome diet during and post-treatment. The need for post-treatment monitoring systems to be developed is also highlighted by the study and can be brought to notice to authorities. These changes combined would be a great step to improving public health crises such as the transmission of infectious diseases in developing countries like India.

INTRODUCTION

Tuberculosis is a contagious disease, caused by the bacterium *Mycobacterium tuberculosis*. It is a serious condition that mainly attacks the lungs (American Lung Association (ALA), n.d.). This bacterium is transmitted through tiny droplets of moisture released in the air via coughs/sneezes or by consuming infected milk/meat (ALA, n.d).. There are two types of Tuberculosis: Latent Tuberculosis and Active Tuberculosis.

Although tuberculosis is highly contagious, it is curable (Gebreweld et al.,2018). Unfortunately, despite the disease being treatable as well as preventable in most cases by following basic hygiene and taking the BCG (bacille Calmette-Guerin) vaccine (Rodriguez, 2009), tuberculosis is still a leading cause of death in many parts of the world. One of the main factors contributing to this high mortality rate is the non-adherence to a complete course of treatment by the patients.

The treatment for tuberculosis usually lasts for 6 months or more. The treatment primarily involves taking oral antibiotics, which are commonly provided using Directly-observed treatment- short-course (DOTS).

Literature on the challenges faced by tuberculosis patients in India while they're treated is not widely available. What is available though is the factors contributing to non-adherence in Indian tuberculosis patients which are closely linked to the challenges faced by them. Below are the main factors identified:

Socio-economic concerns, Transport costs, Stigma, Side Effects and Poor facilities.

METHODS AND MATERIALS

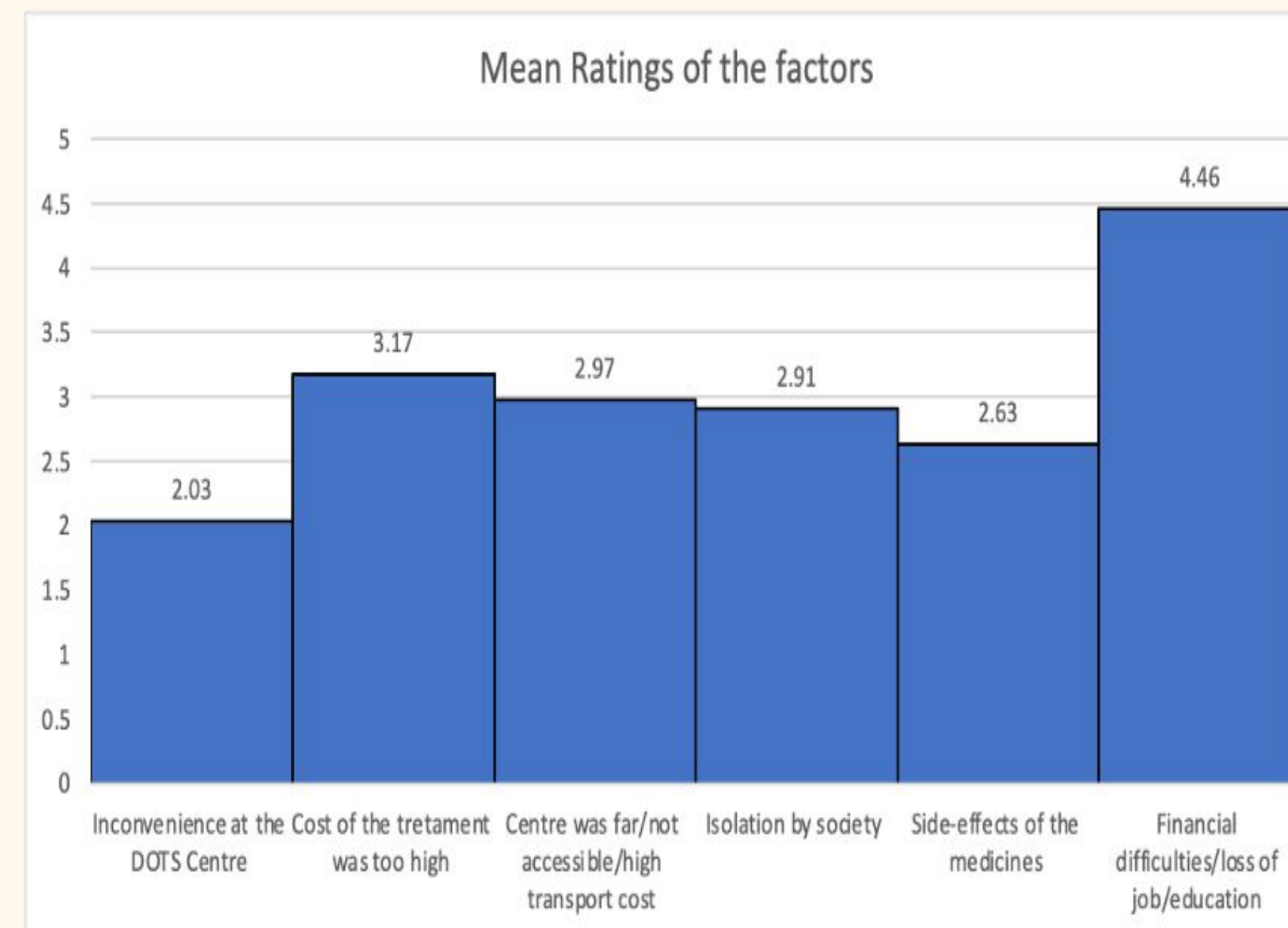
Respondents were asked to rate each of the factors identified in the literature, in terms of their level of importance in influencing the personal difficulties faced by them on a Likert scale of 1-7. The sample consisted of 35 respondents with 19 males and 16 females majorly from South Delhi, all of which belonged to a relatively poor socioeconomic background.

A survey was designed and was conducted in Hindi catering to the comfort of the respondents of this study all of which belonged to the low socioeconomic group in Indian society. Phone calls were then made to the respondents and ultimately, 35 surveys were completed.

Furthermore, the National Institute of Tuberculosis and Respiratory Diseases (NITRD) was visited and its Senior Research Consultant was interviewed. The interviewee specialises in research and deals regularly with tuberculosis patients . The interview lasted for 20 minutes and the key points made by her were noted down accurately, just as she quoted.

Descriptive statistics were run to compare the relative challenge posed by each of the factors to the tuberculosis patients and thus test Hypothesis 1b. Additionally, a t-test for the two samples; males and females was run to test Hypothesis 2b

RESULTS



Difficulty/ challenge faced by patients	Males		Females		t Stat	p
	M	SD	M	SD		
Financial difficulties/ loss of job/education	5.53	2.20	3.19	2.67	-2.78	0.00467

DISCUSSION

The results were in line with the large proportion of people living in poverty in India coupled with the rather long duration of treatment which averages 8 months and 4 days according to the results of this study. It is also interesting to note the correlation and perhaps causation between the prevalence of tuberculosis and poverty. A study conducted amongst Indian tuberculosis patients found the prevalence of the disease amongst those living under the poverty line was significantly higher (242/100,000) than those above this marker (149/100,000).

Respondents also elaborated on this factor by speaking about the additional out-of-pocket (OOP) expenses, borne by them. These included the high cost of medicines as explained by a 70-year old female respondent.

In the case of a then-16-year-old student respondent, the trade-off came in the form of loss of education. She ended up stopping her education after contracting tuberculosis; the irregularity of her school attendance led to her losing interest in her studies. On a larger scale, this loss of education can have serious social and economic implications on the economy of a country. A 2012 report from UNESCO (2012) suggested that for every 1 USD spent.

'Isolation by society' ($M=2.91$, $SD=2.56$) was also found to be a paramount challenge of being a tuberculosis patient in India as confirmed by the study. This was the reason why a 54-year old patient made it a point not to inform his neighbours about his disease because he feared that they would have stayed away from him.

In India, one of the reasons that contribute to the stigmatization of tuberculosis is the high rate of co-infection between tuberculosis and infection by the HIV virus, due to the terminal and sexually transmitted nature of the latter .

The answers of the interview with the researcher also shed light on another reason due to which tuberculosis isn't cured fully and may recur in patients; smoking and alcoholism during and/or post-treatment.

An interesting argument made when asked about why tuberculosis is still so prevalent in India as compared to other countries was that the high population density of India plays a big role in the prevalence of transmissible diseases like tuberculosis in the country. Furthermore, she explained how "monitoring is more rigorous" in countries abroad, possibly due to the small size of tuberculosis patients and a higher Doctor: Patient ratio, which is also a likely cause of the evident difference in the rate of infection and death of tuberculosis between India and other countries.

The results of the t-test, as shown in table 1 are supported by the idea that men are the breadwinners of the house and therefore, disruption to income poses more of a problem to men ($M=5.53$) or households with men who have been affected by tuberculosis, as compared to women ($M=3.41$).

CONCLUSIONS

As discussed above, there are some noteworthy differences in the mean ratings given by respondents to the six challenges identified in this study. These differences can be useful to keep in mind when government sector hospitals, local government bodies, private individuals and firms, research institutions, civil society organisations and international agencies are devising strategies to improve the patient experience when undertaking treatment for tuberculosis and also towards tuberculosis elimination by 2025. The difference between the mean ratings of 'Financial difficulties/loss of job/education' by males and females can also be used to understand how different measures adopted to eliminate TB can be targeted at different genders The study also helps draw an interesting conclusion; combating a disease involves not only medical advancements but also a plethora of reforms in the social and cultural facets of a country. Hence, the role of creating awareness amongst the general population to fight against tuberculosis in developing countries is pivotal.

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