

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 (Statistica, 2019), India recorded 79,000 deaths due to this bacterial infection (The Times of India, 2020). 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. The study was carried out by conducting a survey via phone with 35 Tuberculosis patients. 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.). This transmission is not very rapid and a person is likely to contract the bacterium by living in proximity with another tuberculosis patient for over 24 hours.

There are two types of tuberculosis:

1. Latent tuberculosis infection in which the bacterium remains inactive in the carrier's body and causes no noticeable symptoms. This form of tuberculosis cannot be passed from person to person (Mayoclinic, n.d.). Nonetheless, 5-10% of such patients, particularly those with predisposing factors, such as malnutrition, being HIV positive, having a weak immune system and so on, are susceptible to developing active tuberculosis without treatment (World Health Organisation, 2021). Hence, treatment to pre-empt this development is advised (Harvard Health Publishing, 2019).
2. Active tuberculosis leads to palpable symptoms. The patient's immune system is unable to fight the infection causing the bacteria to spread from the lungs (Pulmonary tuberculosis) to other parts of the body (Extrapulmonary tuberculosis). The bacteria most commonly metastasizes to the lining of the lungs (Pleural tuberculosis), the membrane around the brain and the spinal cord (tuberculosis meningitis),

bones and joints, the lymph nodes, the abdomen (Abdominal tuberculosis), the kidney, the bladder and even the blood (The Conversation, 2019).

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. Without proper treatment, more than half of the people with active tuberculosis will die within five years of initial infection (Harvard Health Publishing, 2019).

In order to ensure that the infection doesn't spread, those with active tuberculosis must undertake their complete course of treatment so that the antibiotics continue working to fight the infection (Rodriguez, 2009) and the pathogen doesn't develop resistance against the antibiotic. The treatment for tuberculosis usually lasts for 6 months or more. The treatment primarily involves taking oral antibiotics such as Isoniazid, Rifampicin, Ethambutol and Pyrazinamide. These drugs are commonly provided using Directly-observed treatment- short-course (DOTS). This is a holistic public health strategy for the complete treatment of tuberculosis including the diagnosis, bacteriology, provision and maintenance of a record of the drugs received, chemotherapy and thus ensuring the patient's adherence to treatment (Gursimrat K Sandhu, n.d.). In some cases, patients may be infected with strains of the bacterium that are resistant to most antibiotics, leading to DR-TB (Drug-Resistant tuberculosis) which can take up to 24 months to treat (Harvard Health Publishing, 2019). It is thus evident that the treatment is time-consuming, but indispensable. Without proper treatment, more than half of people with active tuberculosis will die within five years of initial infection (Harvard Health Publishing, 2019).

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:

First, socioeconomic concerns play a major role in non-compliance to treatment and this factor would presumably be more prevalent in low- and middle-income countries. Many patients lost time while undertaking treatment and this was directly related to a potential loss of wages and work time. 13.43% of the respondents of a study conducted in India were anxious that undertaking this long course of treatment would adversely affect their opportunity to work and they were anxious about losing wages (Rai et al.,2015).

Secondly, factors associated with transport were major inhibitors to adherence to treatment. Interviews carried out with 156 tuberculosis patients in Mumbai(Bagchi et al.,2010) found that patients had to travel to TB-DOTS centres thrice a week to receive their prescribed dose of medication. A comprehensive study from India on a cohort of 650 patients from Chennai, Vellore and Mumbai showed that those who took more than 30 minutes to collect their medicines had much greater odds of leaving the treatment mid-way (Subbaraman et al.,2021).

Another salient factor identified was the stigma associated with tuberculosis. There are two parts to this. First, many patients are fearful of not having a place to live once their communities know about their infection. The other is the high level of coinfection between HIV and Tuberculosis. HIV is a virus that attacks the immune system of a person and carries a higher level of stigma since it is incurable. Although it is true that those with HIV are more likely to develop Tuberculosis due to their weakened immune system, this is not always the case and many people blindly draw an association between the two. Fighting the stigmatising comments and being socially isolated led to many patients being irregular about their treatment and visits to the clinic (Skinner & Claassens,2016). A respondent from a study conducted in Karnataka, India stated, "*When doctor told me that I have TB, I was shocked and I thought I will die soon, I was also worried about how my family would treat me*" (Geethalakshmi RG et al.,2019,p.3)

Many patients also expressed side effects as a concern. A study from Madhya Pradesh, India (Rai et al.,2015), showed that 34.33% of the patients were non-compliant to treatment because of the side-effects of the drugs, such as vomiting, nausea and loss of appetite.

In addition to this, poor facilities were also positively associated with non-adherence to treatment in Tuberculosis patients. A study conducted in South Africa identified that problems such as long queues, shortage of medicines and negative staff attitudes at the facilities were inhibitors to complete the treatment for many patients (Skinner & Claassens,2016).

A qualitative study conducted in Ukraine on 60 tuberculosis patients found some challenges commonly faced by them while undertaking treatment. The first was the financial cost of tuberculosis. The majority in the sample were unemployed and very few received sick/disability pay during this time. The crisis was accentuated by imaging and costs of medicines. Many respondents were emotionally challenged due to family separation, in addition to the poor facilities at the tuberculosis hospitals. A respondent stated, “ There is nothing comfortable there”. Patients felt as though the healthcare workers lacked warmth. One of them described her experience as, “ It’s hostile. Awfully hostile. The doctor is just an overseer.” Patients also described fear and anxiety of their own morbidity as a challenge they faced while admitted.

Furthermore, many respondents felt that taking multiple pills at once was challenging. Finally, almost all participants of the study expressed their concerns about how “ people’s attitude” “ change”. Some respondents believed that tuberculosis was common amongst certain people who indulge in activities like sharing needles, being prisoners, living in unhygienic conditions etc. Many were fearful that they would be isolated by friends and family and hence chose self-treatment over hospital care (Aibana et al., n.d.).

There have been multiple studies in the past to identify and evaluate the factors that contribute to non-adherence in tuberculosis patients in India. However, there is no concrete study on the challenges faced by Indian tuberculosis patients in New Delhi, India. This study aims to identify the same, primarily using a qualitative analysis. Qualitative interview responses have also been included in the study to enhance the analysis. The results of the study may be used to find ways to ease these challenges for these patients so that they would be willing to sustain their treatment and recover from the illness.

Methodology

Research Aim and Approach

The aim of this research study was to identify the challenges faced by Indian tuberculosis patients visiting a clinic in South Delhi while undertaking treatment for tuberculosis and evaluate their relative importance through a mixed-method approach. More specifically, recovered Indian tuberculosis patients visiting this clinic were asked to complete a primarily close-ended survey conducted over a phone call. The key difficulties identified through a thorough reading of the literature were incorporated into the questionnaire (see Appendix A):

1. Inconvenience faced at the Directly Observed Treatment, Short- centre (DOTS Centre) such as time delays, supply shortages etc;
2. Stigma towards the disease;
3. Cost of the treatment and medication;
4. Transport issues;
5. Side-effects of medication; and
6. Disruption to work and income.

Respondents were asked to rate each of the factors, in terms of their level of importance in influencing the personal difficulties faced by them on a Likert scale of 1-7, with 1 being ‘Not important at all’ and ‘7’ being ‘Very Important’. 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. The relevant hypotheses tested were as follows:

Null Hypothesis 1a: There is no difference in the mean ratings of the importance of the challenges faced by Indian tuberculosis patients living in New Delhi.

Alternative Hypothesis 1b: There are differences in the mean ratings of the importance of the challenges faced by Indian tuberculosis patients living in New Delhi.

Furthermore, the differences between the ratings for the various factors between male and female respondents were examined;

Null hypothesis 2a: There would be no significant differences between the extent of difficulty that male and female respondents' faced due to any of the six factors.

Alternate Hypothesis 2b: There would be significant differences between the extent of difficulty that male and female respondents' faced due to any of the six factors.

Data Collection Procedure

A regional Dispensary in Sainik Farms, New Delhi was contacted to get the names and telephone numbers of over 100 past tuberculosis patients. Subsequently, a survey was designed that consisted of questions asking for the age and gender of the respondent, along with the duration of tuberculosis treatment undertaken by them and the duration of tuberculosis treatment they were recommended to undertake by their doctor. The next component of the questionnaire was a table comprising six factors to be rated on a Likert scale ranging from 1-7, with 1 being 'Not important at all and 7 being 'Very important' (Appendix A). The survey 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 interview was conducted in order to not only facilitate but also enhance the process of analysing the quantitative results obtained in the study. Medicine is a field that requires one to dig much beyond the face value of the statistical results and hence the answers to the open-ended interview questions certainly made the analyses of the results more holistic. A visit to NITRD was made and a presentation was given to the Chief Medical Officer, who further connected to the Senior Research Consultant. The interviewee specialises in research and deals regularly with tuberculosis patients and therefore has years of experience as well as a fresh perspective on the challenges faced by both patients and doctors dealing with tuberculosis. The interview lasted for 20 minutes and the key points made by her were noted down accurately, just as she quoted. The two primary questions of the Interview were:

1. What do you think is the biggest obstacle faced during the treatment of tuberculosis by both doctors and patients?
2. Despite there being the same medicines and treatment plans available for tuberculosis worldwide, why is India still a victim of this disease in large numbers whereas other developing, developed nations are not?

In conjunction with the answers to these questions, the researcher provided other valuable and interesting information to ponder and include in the analyses of the research study.

Data Analysis

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. All the textual data, whether they came from the open-ended questions of the survey or the interviews, were analysed to provide supplementary evidence that could enrich the understanding of the phenomenon under investigation.

Results and Discussion

In this section of the paper, all the relevant results from the ‘Description of the Research Study’ are presented, including both statistical and qualitative analyses. The respondents' ratings of the relative impact of the problems faced during their course of treatment for Tuberculosis in clinic of South Delhi; their relative importance; the time period for which the respondents undertook treatment; and the differences in the extent to which each of the identified factors posed a problem as a result of the differences in the time of treatment were analysed (see raw data in Appendix B). The section also includes qualitative responses that help to highlight additional perspectives, enhancing the study.

Analysis of the relative importance of the six challenges

This section explores the relative challenge of the 6 identified factors posed to the respondents while they undertook treatment for tuberculosis in New Delhi, India in addition to exploring the differences between the ratings of each of the factors by males and females. It is evident from the descriptive statistics (Table 1) that ‘Financial difficulties/loss of job/ education’ ($M=4.46$, $SD=2.67$) was the biggest challenge faced by patients undergoing tuberculosis treatment in New Delhi, India. This was followed by ‘Cost of the treatment being too high’ ($M=3.17$, $SD=2.48$); ‘DOTS Centre being too far’ ($M=2.97$, $SD=2.24$); ‘Isolation by society’ ($M= 2.91$, $SD=2.56$); and ‘Side-effects of the medicines’ ($M=2.63$, $SD= 2.43$). The least significant issue faced by the patients was ‘Inconvenience at the DOTS centre’ ($M=2.03$, $SD=2.09$).

Table 1

Descriptive Statistics: Ratings of the Various Challenges Faced by Indian Tuberculosis Patients (N=35)

	Inconvenience at the DOTS centre	Cost of the treatment was too high	Centre was far/not accessible/ high transport costs	Isolation by society	Side- effects of the medicines	Financial difficulties/ loss of job/education
Mean	2.03	3.17	2.97	2.91	2.63	4.46
Standard Error	0.35	0.42	0.38	0.43	0.41	0.45
Median	1	1	2	1	1	6
Standard Deviation	2.09	2.48	2.24	2.56	2.43	2.67
Count	35	35	35	35	35	35

Graph 1

Graph comparing the mean ratings of the six factors.

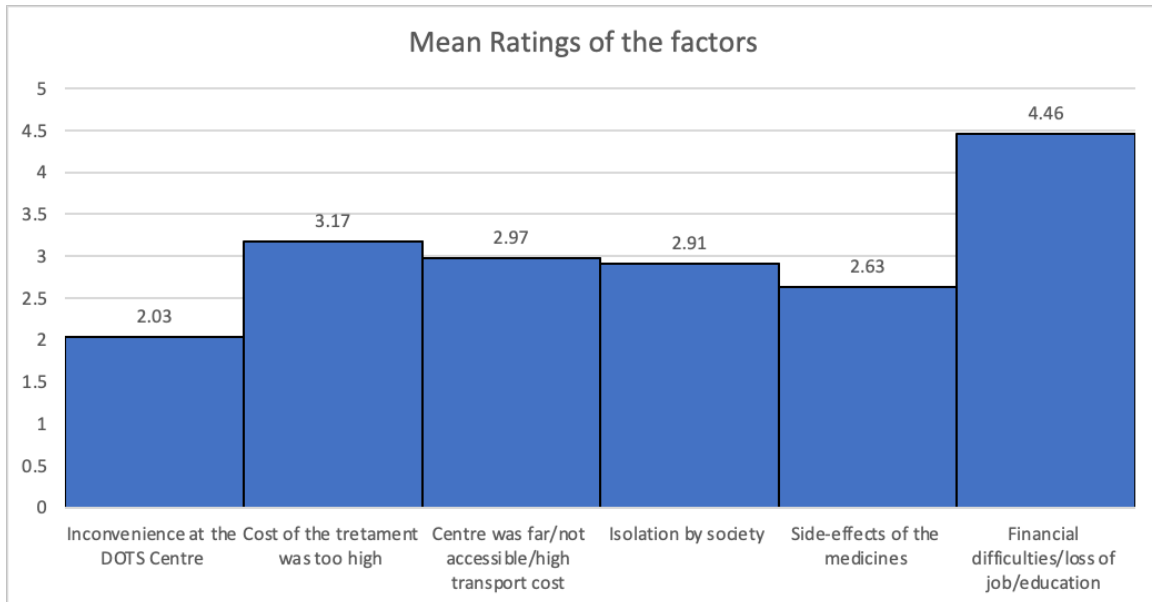


Table 2

t-Test: Two-Sample Assuming Unequal Variances

Table showing the presence of statistically significant differences between the mean ratings for the factor 'Financial difficulties/ loss of job/education' by males and females. (N=35)

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

Note.*p < .01

The results obtained from the surveys, summarised in Table 1 and Graph 1 were coherent with what was expected based on literature and were also strengthened by qualitative responses given by the respondents of the study.

The results of the study were used to compare the relative challenge posed by each of the factors to the patients undertaking treatment for this disease. It was found that financial losses presented the highest mean rating ($M=4.46$, $SD=2.67$), which was not entirely surprising. This was 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. According to the United Nations, 28% of India's population is considered to be poor (DownToEarth, 2021). 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) (Muniyandi & Ramachandran, 2008). One of the respondents of the study,

a 13-year old male explained that he left treatment since his father had no job during the lockdown and that he would be willing to resume treatment once their financial conditions were better. 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 and payments for a healthy, nutritious diet he was asked to take by doctors when he was undergoing treatment for tuberculosis as explained by a 60-year-old male respondent. In fact, the reality that patients in India cannot afford nutritious meals during their course of treatment is a major cause of delayed recovery, as emphasised by the Senior Research Consultant From the National Institute of Tuberculosis and Respiratory Diseases (NITRD) (personal communication, August 11, 2021).

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 on education, the economy grows by 10-15 times.

'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. According to him, no one stayed away from him since he hadn't informed anyone. In fact, social stigma has previously been known to be a barrier to the initiation and adherence to treatment for some diseases, especially transmissible, sexually transmitted and terminal illnesses etc. (Shah et al., 2020). 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 (Courtwright & Turner, n.d.). This stigma can lead to the isolation of the patient and pose a hindrance to their treatment. In fact, Dr Jennifer Furin, a lecturer at the Harvard Medical School explains that delayed diagnosis remains a key reason behind the high tuberculosis mortality rate in India (Sachdev, 2017). The delayed diagnosis, additionally, is a result of stigma against the disease (Courtwright, Turner, n.d.). It would thus be reasonable to say that one of the primary reasons for the spread of this disease across communities in India is the stigma against it.

It is also worth noticing that the mean ratings across the board of factors range from 2.03 to 4.46 and although 'Financial difficulties/loss of job/ leaving school', 'Cost of the treatment was too high' and 'Isolation by society' pose to be the biggest challenges, other factors also have values that are not far from these. Therefore, none of the problems evaluated should be completely ignored when devising plans to resolve the difficulties faced by Indian tuberculosis patients while undergoing treatment.

The challenges expressed above are all from a patient's perspective. However, they vary from that of a Doctor, for whom non-adherence is the biggest obstacle to overcome. All of the challenges stated above contribute to the non-adherence to treatment as explained by the senior research officer specialising in Epidemiology & Pub. Health at NITRD who was interviewed as part of the research study.

"The moment they feel well, they become irresponsible (and tend to leave the treatment midway). They're all (still) spreaders and carry the disease". Not part of the challenges faced by patients, but this indifference to treatment has been identified as one of the key factors contributing to non-adherence of treatment by tuberculosis patients. Patients start to feel better a few weeks after initiation of treatment and may be under the wrong impression that their disease is cured when this is not really the case (Kulkarni, et al.). 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.

The senior consultant expressed her concerns about post-recovery problems by stating, *"10-15% of the patients don't stop smoking"* while or after treatment which is a significant barrier to full and rapid recovery. It is widely known that smoking shows a direct relationship with the occurrence of tuberculosis, recurrence of the disease and also impedes patients' response to the treatment (World Health Organization, 2018). Despite multiple warnings by doctors, many tuberculosis patients, not only in India but also worldwide continue to smoke and engage in alcohol consumption, escalating the graveness of the situation. In addition to the above factors, the interviewee at NITRD listed other challenges faced by patients accentuating their non-adherence to treatment.

These factors were in line with the results of the quantitative responses we received from the survey and hence helped validate them.

“(there could be) adverse drug reactions”, sometimes patients have to go for more expensive private treatments since the “timings don’t suit” them at public DOTS centres.

The first factor she mentioned is related to ‘Side-effects of the medicines’ ($M=2.63$, $SD= 2.43$). Some common side-effects associated with tuberculosis treatment include fever, pain in the lower abdomen, nausea, vomiting, loss of appetite, fatigue and rashes. The discomfort caused to patients along with hindrance to their daily activities due to these side-effects often promote non-adherence to treatment. This is not only the case for tuberculosis but also a large number of diseases worldwide. The second factor she touched upon falls under ‘Inconvenience at DOTS centre’ ($M=2.03$, $SD=2.09$). While this received the lowest mean rating in the study, the doctor highlighted that DOTS centres have particular timings for the collection of patients’ daily medication. If these timings don’t suit them, the patients may have to go for treatment at private hospitals/clinics which is certainly a more expensive option and problematic for many.

Although non-adherence is a major reason for the high mortality rate associated with tuberculosis in India (32/100,000 as of 2019), it would be rational to believe that other factors contribute to this high death rate as well. Despite non-adherence being prevalent in a large number of countries, India still holds the largest share of tuberculosis deaths worldwide. The difference between the mortality rates of this disease in India as compared to the western world is astonishing given that the drugs used, such as isoniazid and rifampicin are standardised worldwide. 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.

Another aspect that was analysed from the data collected was the differences between the ratings given to the six factors between males and females. The results showed that only one of the factors, that is ‘Financial difficulties/loss of job/education’ had statistically significant differences between the two groups: $t(35)=-2.78$, $p<.05$. The results for the same are summarised in Table 2. These results may be attributable to the existence of significant gender stereotypes in India, just like many other developing countries. The idea that men are the bread-winners of the house is still more than common in the country. According to data collected by the International Labour Organisation, as of 2019, women in India form a mere 20.317 % of the labour force, while the other 160 million are homemakers. These statistics are coherent with the result of the study which shows that 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 ($M=3.41$). Furthermore, the school enrolment, primary and secondary, gender parity index in India was 1.08 as of 2017, higher than many other countries. This could also be used to explain why males were more affected by loss of education due to tuberculosis since a large proportion of girls in India are not even enrolled in secondary education.

Conclusion

The research study focuses on the challenges faced by Indian tuberculosis patients visiting a dispensary in South Delhi while undertaking the treatment for tuberculosis and evaluating their relative importance. Based on the results in Table 1 and Graph 1, there are differences in the respondents’ mean ratings of the levels of importance of ‘Inconvenience at the DOTS centre’, ‘ Cost of the treatment was too high’, ‘ Centre was not accessible’, ‘ Isolation by society’, ‘ Side-effects of the treatment’ and ‘Financial difficulties/loss of job/education’. Therefore, the null hypothesis 1a set out in this research study that there is no difference in the mean ratings of the challenges faced by Indian tuberculosis patients can be rejected. There is also a statistically significant difference between the male and female respondents’ ratings of ‘Financial difficulties/loss of job/education’, and therefore null hypothesis 2a can also be rejected.

This section explores the relative challenge of 6 factors posed to the respondents while they undertook treatment for tuberculosis in New Delhi, India in addition to exploring the differences between the ratings of the factors by males and females separately.

The study found that ‘Financial difficulties/loss of job/education’ was the paramount obstacle faced by patients while undertaking treatment for tuberculosis. This factor had the highest mean rating out of all the six factors. On the other hand, the lowest mean rating was that of ‘Inconvenience faced at the DOTS centre’ . This could suggest that the efforts made by the Indian government to combat tuberculosis by 2025 as part of the TB National Strategic Plan such as the provision of evening DOTS in Chennai, India, has been helpful in alleviating convenience issues (‘India TB Report’, 2019). Qualitative responses of the respondents and the Senior Research Consultant highlight that the time period post-treatment is also crucial for tuberculosis patients and must include a nutritious diet - which is deemed expensive by a majority of the patients. They should also refrain from smoking or alcohol — two activities that can harm the lungs even more and also lead to accentuated side-effects of the tuberculosis treatment.

This study also presented a relatively high rating given to ‘Isolation by Society’ , which is a reflection of the stigma prevalent in the society of many developing countries like India, especially against infectious diseases such as tuberculosis. Another reason for such an attitude besides the infectious nature of the disease is its association with AIDS which is a sexually transmitted disease as explained in the ‘Introduction’ section.

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 and the study can be extended to explore whether these differences are also prevalent between different socioeconomic or age groups. 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. The National Strategic Plan for Tuberculosis Elimination (NSP) suggests the use of mass media, trained public health volunteers, and community engagement to create widespread knowledge of the symptoms of tuberculosis amongst communities facilitating the identification of tuberculosis patients (‘National Strategic Plan for Tuberculosis elimination 2017-2025’, 2017).

Implications

- First, in order to tackle the financial difficulties faced by patients, more emphasis has to be laid on the provision of financial support to patients while undertaking treatment, besides just the provision of free medicines. The NSP also highlights the need to tackle this issue and suggests strategies such as increased social support and health insurance for tuberculosis patients. In line with the interviewee’s views on the importance of wholesome meals during and post-treatment, more money has to be allocated by governments towards the provision of nutritional support to patients who otherwise find it a financial strain to pursue a nutritious diet.
- Second, in order to overcome the social stigma prevalent against tuberculosis in India, awareness about the causes, symptoms, and cures of tuberculosis has to be spread. To induce a change in the attitude of people is challenging and one key method would be sensitization of the community via mass media, including TV advertisements, flyers and posters. Furthermore, as outlined in the NSP, the provision of counselling services for tuberculosis patients to not only encourage the completion of their course but also reduce the stigma against the infection could be implemented by hospitals.

- Another way to tackle this would be to target school-going students. Schools, especially in areas of high infection risks, can be persuaded to introduce the epidemiology, causes, symptoms and cures of infectious diseases like tuberculosis as part of the curriculum for high school students. This could help induce a more responsible and less biased mindset amongst them towards tuberculosis and ensure that the stigma does not deepen in the future.
- In continuation, the realisation that this stigma is dominant amongst the lower strata of Indian society, conducting tuberculosis drives, for instance, in the squatter settlements of New Delhi, targeting the less educated population might be successful in destigmatising the idea of contracting tuberculosis and encouraging treatment.
- The upper strata of society could also be sensitised towards the plight of the tuberculosis situation in the country and donations can be collected which could be used to combat the financial strains faced by at least a few families due to tuberculosis.
- The NSP has also recommended the use of HIV-TB peer educators for community intervention and the creation of more physical and virtual safe places where patients can seek information about their disease and its treatment.
- Another finding of this study, that is the need for improved monitoring of patient medication and adherence also demands urgent action in order to combat tuberculosis recurrence and deaths in India. This has been addressed with the development of a web-based surveillance system called 'Nikshay' and an increase in DOTS accessibility across the country. The e-Nikshay platform provides SMS support services for alerts, counselling and awareness about tuberculosis. Moreover, the invention of the Medication Event Reminder Monitor (MERM) device as a means to remind patients and continually keep track of their medicine intake has also been an addition to the monitoring system for tuberculosis in India.

Readings all sorts of headlines such as India being the tuberculosis capital of the world and having the highest tuberculosis burden amongst all developing nations encouraged me to study the reason behind this, especially since India has been making breakthroughs across interdisciplinary fields in medicine and yet is unable to tackle this endemic infection with a standard, known treatment protocol. The two primary reasons that came across in the literature and through the interview conducted with a professional in the field were the high population density in the country and non-adherence to treatment. The collection of data, however, on non-adherence was not plausible due to the stigma prevalent against the disease. When respondents were asked as to whether they completed their treatment or not most replied positively which contradicted the opinions of several experienced doctors on the same. Patients were not comfortable confessing to leaving their treatment mid-way as they felt judged and frowned upon. Thus, the data was instead collected on the challenges faced by tuberculosis patients during their course of treatment and this was directly associated with the factors that could potentially cause non-adherence, which is one drawback of the study. This problem could be avoided by talking in person to the respondents making them feel that they're in a safe space and hence reply more honestly to the questions asked. This was not possible, however, due to COVID-19 restrictions. In addition to this, the small sample size of 35 patients was used in the study due to a lack of access to the contacts of past patients adhering to the guidelines of patient confidentiality. Risks of infection associated with the COVID-19 pandemic didn't permit the physical collection of responses. Furthermore, the handicap of this stratum of society- most of which isn't literate enough or doesn't have access to technology prevented the survey from being conducted online.

It is pivotal to understand that elimination of tuberculosis in India is possible and doesn't require changes in the medical practises employed to tackle the disease but rather changes in the social and cultural practises to do so. We must hence work actively towards the elimination of tuberculosis in India by 2025 to get rid of the economic weight that the disease burdens the healthcare system of the country with.

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