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# COST OF CARE IN TB PATIENTS, ITS SOCIAL IMPLICATIONS AND IMPACT ON MANAGEMENT OF PATIENTS

Respiratory Medicine

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## ABSTRACT

**Introduction:** Tuberculosis is an increasing problem for the developed world, particularly among the economically deprived. TB patients have to suffer poverty because of cost of treatment as well as DALY lost. TB is not only a medical disease but it has a wider ramification on the socio-economic as well as the psychological aspect of patient, The increasing cost of care in acts as a barrier for achieving optimum management and sometimes disproportionately affects the outcome. **Aim:**To study the expenses incurred by TB patients both direct and indirect, to account for the social implications of TB in the society and how it affects the management of such patients . **Material and Methods:** This Hospital based study including IPD and OPD patients in Respiratory Medicine of Maharishi Markandeshwar Institute of Medical Science And Research, Mullana (Ambala) (Deemed to be University), using a semi structured questionnaire was used to interview the patients regarding the various expenses they had during the treatment, how it affected their social life and any complications they faced. The results were analysed with similar studies conducted previously in different countries. **Results:** Pre-diagnostic/diagnostic costs were Rs 2738.20 and Rs 5072 respectively. Total cost during treatment and total guardian costs were Rs 1604 and Rs 5928.57 respectively. Total mean annual income of the patients was Rs 209320 while total mean cost for TB treatment was Rs 29316.60. Of the total 100 patients, 74 went to government centres and 26 went to private for treatment, the most common reason for choosing private facilities was that it was time consuming followed by Distance to facility. 20% people sold some sort of property to finance treatment.24% people faced catastrophic costs of Tb and 77% patients who incurred catastrophic costs had some form of post treatment complications **Conclusion:** There are many indirects costs in TB treatment that are not accounted for, the expenses lead to catastrophic costs for the patient as well as the household. The social implication of Tb including loss of job and separation from friends spouse and family, Catastrophic patients are associated with adverse outcome and the patients had to pay over and above the treatment cost due to complications arising from tuberculosis and led to stopping of treatment in between.

## KEYWORDS

Catastrophic costs, Tuberculosis, expenses, society, stigma, complications,

## INTRODUCTION:

Tuberculosis is a disease that disproportionately affects the poor. TB programs therefore need to ensure that the economically and socially disadvantaged groups do not face barriers that keep them from seeking treatment. In addition, TB programs need to ensure that TB doesn't stand at the beginning of a spiral into (deeper) poverty. Tuberculosis (TB) is an ancient human disease caused by *Mycobacterium tuberculosis* which mainly affects the lungs, making pulmonary disease the most common presentation (K Zaman, 2010). However, TB is a multi-systemic disease with a protean presentation. The organ system most commonly affected include the respiratory system, the gastrointestinal (GI) system, the lymphoreticular system, the skin, the central nervous system, the musculoskeletal system, the reproductive system, and the liver.

The Costs in TB care includes both direct costs like treatment expenditure, money spent for investigations, costs incurred by nutrition and indirect costs like the transport costs and loss of pay due to inability to work. The other aspect of expenditure in TB is the social costs- it amounts for the loss of wages incurred by the patients wife or any bystander of the patient. Children may have to leave school, guardians may have to leave the job or may get laid off by the employer because of non attendance or poor performance.. Stigma in social settings due to TB is also an instigating factor. There may be disruption in the family/ spouse may be forced to leave the house. Patients may have to sell off property or immovable assets to settle debts. This often leads to loss of follow up and adherence to treatment regimen. Some have tried to overcome this burden by using insurance schemes both National and community based.

Due to heavy costs incurred and the long duration of the illness , some patients tend to discontinue treatment. Discontinuation of tuberculosis treatment and restarting it on will leads to many problems including development of drug resistant tuberculosis. Thus a simple 6month long treatment modality is changed to strenuous resource depleting multi drug resistant drug protocols. Tuberculosis produces many complications in certain individuals leading to permanent morbidities in them, which they did not have prior to treatment, this further impacts the management of such cases and further eats into the economic burden of the patient.

## MATERIALS AND METHODS:

The study was conducted in Department of Respiratory Medicine. 100 patients admitted in our hospital for tuberculosis were taken up for study after taking due consent. The patients fulfilling the inclusion criteria and after verifying the exclusion criteria were taken up for study. A mixed methods (explanatory) design with cross-sectional quantitative and in-depth qualitative interviews was used. While the quantitative results will estimate the magnitude and pattern of costs, the qualitative results will give us an insight into perspectives of the patients toward costs for TB care and understand the choices they made along their pathway to care.

An interview questionnaire adapted from the KNCV 'Tools to estimate Patients Costs' was modified for the Indian context and used. Patients were interviewed in OPD or in IPD to recall the expenses they incurred during treatment and kuppuswamy scale was used to classify them according to social classes, the post treatment complications were assessed and enumerated.

The analysis included the distribution of patients according to gender and social class. Quantitative assessment of the cost in rupees was calculated. Descriptive statistics frequency analysis, percentage analysis were used for categorical variables and the mean , median, IQR & S.D were used for the continuous variables. All analysis were done using SPSS software, version 23.0.

## RESULTS:

- Out of 100 patients, males were 66 and females were 34.
- Pulmonary smear was positive in 70 percent of the cases. Extrapulmonary TB was present in 22 percent of the cases.
- Maximum duration of treatment was 15 months seen in 10 patients and minimum was 1 month seen in 12 patients.
- Intensive phase of therapy going on in 30 percent of the patients, while 44 percent of the patients were in continuation phase. Treatment was completed in 26 percent of the patients.

- DSTB 84 patients and DRTB 14 patients.
- 4 patients were HIV positive and all of them had catastrophic costs
- 36 patients were previously treated and 64 were first time TB patients.
- 20 patients had completed the previous treatment and 16 stopped treatment in between the reason for stopping treatment was lack of money in 6, drug side effects in 6, moved to other place in 2 and other causes in 2 patients.
- On appearance of first symptom, 24 reported to district hospital, 30 to dispensary, 16 to health centre, 4 to mission hospital, 2 to pharmacy drug and grocery store and 24 to private hospital/clinic.
- Patients who visited Private clinics/shops 26% and Government centres 74%
- Reason for not obtaining health facility was distance to facility in 14, too expensive in 6, time consuming in 20, lack of available facilities in 6, mistrust in govt. health service provision in 4 and others in 2 patients.
- Hospitalization was seen in 46 patients and not in 54 patients.
- Most common comorbidities were seen in patients having COPD and hypertension seen in 10 followed by hypertension alone in 6 patients.
- 46 patients had insurance and 54 had not.
- 14 patients borrowed money from family and 18 from neighbours/friends.
- 20 patients sold any property to finance the cost of TB illness.
- Maximum number (8) of patients sold farm followed by livestock (6), land (2), transport (2) and household item (2) to get treatment.
- 64 patients cut their expenses on other things in order to cope up with TB treatment.
- Level of education was primary in 34, secondary in 20, graduate in 4 and not attended in 42.
- 24 were employed, 26 not, 14 were on sick leave, 20 were retired, 8 were in school/ college and 8 were household.
- 20 were salaried person out of which 18 had to use paid leaves and unpaid leaves due to the illness, 22 people changed job due to TB and its treatment, 26 were forced to leave their job/work due to the illness, 28 got separated from spouse/partner/friends, 18 had disruption of sexual life, 10 had sick child due to TB.
- Out of 100 patients, 24 experienced catastrophic costs and 76 were non- catastrophic.
- Common complications were relapse seen 17 in non- catastrophic and 19 in catastrophic, aspergilloma 1 in non- catastrophic and 3 in catastrophic, bronchiectasis 12 in non- catastrophic and 18 in catastrophic, pleural effusion 6 in non- catastrophic and 10 in catastrophic, fibrothorax 14 in non- catastrophic and 16 in catastrophic, pneumothorax 4 in non- catastrophic and 6 in catastrophic and TOPD/COPD 9 in non- catastrophic and 5 in catastrophic.
- 20 patients incurred catastrophic even during intensive phase of treatment, 14 of non- 30 patients incurred catastrophic costs in continuation phase and
- Pre-diagnostic/diagnostic costs were Rs 2738.20 and Rs 5072 respectively. Total cost during treatment and total guardian costs were Rs 1604 and Rs 5928.57 respectively. Total mean annual income of the patients was Rs 209320 while total mean cost for TB treatment was Rs 29316.60 respectively.

**DISCUSSION:**

In this study out of 100 patients, males were 66 and females were 34. Pulmonary smear was positive in 70 percent of the cases. Extra pulmonary TB was present in 22 percent of the cases. DSTB was seen in 84 and DRTB in 14.

In present study, out of 100 patients, 24 were catastrophic and 76 were non- catastrophic. Our results were in concordance with the results obtained by Stracker N et al who also reported similar range of catastrophic patients. In their study, 28% of the participants experienced catastrophic cost.[1]

Recent WHO prevalence surveys in Myanmar and Viet Nam have reported a very catastrophic cost of 65% and 63% respectively.[2]

In a study conducted by Fuady A et al, 33 percent of the patients had catastrophic cost. Wingfield T et al have reported catastrophic costs in 39% of the patient population.[3,4]

In a study conducted by Prasanna T et al, 32.4% of households experienced catastrophic costs due to TB care. Sarin R et al, in their study reported that 7% of TB patients recorded in RNTCP under Delhi state had to suffer catastrophic costs due to TB.[5,6]

We found that 10 non- catastrophic and 20 catastrophic were in intensive phase of treatment, 14 of non- catastrophic and 30 catastrophic were in continuation phase and 16 of non- catastrophic and 10 of catastrophic had completed treatment. Our results were in concordance with the results obtained by previous authors who also reported similar findings. Wingfield T et al also reported that catastrophic population was significantly associated with adverse events and adverse outcome. In another study conducted by Batte et al, the proportion of patients households experiencing catastrophic total costs was 53.1%; with 65.4% and 46.4% the poorest and richest household respectively. They also observed that catastrophic cost was significantly higher in patients with poor socio-economic status.[7] In the study by Prasanna T et al, significantly higher catastrophic costs were present in patients with HIV co-infection and hospitalization. Pledging jewels and borrowing money were major coping strategies.

The high prevalence of catastrophic costs despite publicly available health care in an upper-middle-income country is worrying, and suggests great inequities in wealth and health care access. Foster et al., who conducted a patient cost study in urban and rural areas of seven South African provinces, reported a 2.7-fold greater odds of catastrophic costs in rural than in urban communities. Those findings suggest that social protection and enhanced service delivery and financing interventions tailored to rural settings will be important considerations in countries such as South Africa if we are to reach the target of zero TB-associated catastrophic costs.[8]

Prasanna et al, in their study, reported that catastrophic costs were more common in 45 to 60 years of age. Among hospitalized patients, 45.7 percent were catastrophic while among non-hospitalized 21.4 percent were hospitalized.

Sarin et al also reported that catastrophic costs were significantly more common in males and among subjects with annual income of less than Rs 1 lakh. Interventions to addressing varying qualities of care at multiple care providers towards access to high-quality care could reduce a good portion of catastrophic cost.[9] Muniyandi M et al estimated the occurrence of catastrophic costs associated with TB diagnosis and treatment.. The proportion of patients with catastrophic costs was 31%. Indirect costs were more than direct costs and it contributed majorly to catastrophic costs.[10]

Tuberculosis care, while life-saving, can often be costly to patients. This study establishes and quantifies the extra costs borne by TB patients both direct and indirect and found that a significant amount of money is spend on Indirect causes and hidden charges, we normally compute only the cost of care incurred by the patients but sometimes the guardian who accompanies the patient also experiences expenses which are hidden, as found in the study the most common cause of the guardian accompanying the patient is due to the distance from the facility, if government clinics were nearby patients would not have much travel and guardian expenses, Patients who incurred Catastrophic costs had more treatment complications than those who did not, This was a vicious cycle, catastrophic costs were incurred by patients who had a serious form of the disease like MDR TB or TB associated with HIV, all patients of TB associated with HIV had incurred catastrophic costs also because of the complications they had to spend more for symptomatic medications and comorbidities The catastrophic costs due to TB has led patients to discontinue treatment which resulted in loss of adherence to regimen The tuberculosis entails not only an economic constraint it also led to social problems. Separation from family, friends and the society was a major social implication the tuberculosis patients had followed by loss of job/ forcefully made to quit job and to a lesser extent disruption of sexual life. Patients reported many disruptive social problems due to tuberculosis many of them had to leave jobs because of the stigma associated with TB along with their general disbility to work. Many patients reported that even when they were fit to work they were forced to quit because of ostracisation prevalent in work environment. This was not only at work 26% reported that they were not able to interact in the society due to their condition even with family and friends, this creates a negative impact on the social lives of the patients.

Catastrophic patients are associated with adverse outcome and the patients had to pay over and above the treatment cost due to complications arising from tuberculosis and stopping of treatment in

between. The social implications of tuberculosis were equally distressing as the economical part, money, when it might not be a major factor for providers to decide on the treatment of TB, plays a major role in the receivers perspective and often influences the choices he makes which may not be most beneficial for his treatment outcome.

## CONCLUSION:

Tuberculosis care, while life-saving, can often be costly to patients. This study establishes and quantifies the extra costs borne by TB patients in accessing TB diagnosis and treatment.

The patients who incurred Catastrophic costs had more treatment complications than those who did not.

The catastrophic costs due to TB has led patients to discontinue treatment which resulted in loss of adherence to regimen Seperation from family, friends and the society was a major social implication the tuberculosis patients had followed by loss of job/ forcefully made to quit job and to a lesser extent disruption of sexual life Guardian costs were high due to loss of job and travel along with food on the day when accompanying the patient The patients who had not completed treatment the most common cause was loss of money and job followed by side effects due to TB ad distance to treatment facility Costs borne by patients are due to travel, accommodation and food costs, which has an impact on household income and contributes to a major part of the indirect costs. TB diagnostic and treatment services need to be further decentralised and made available within the reach of patients.

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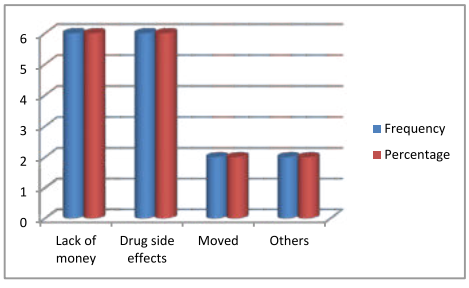
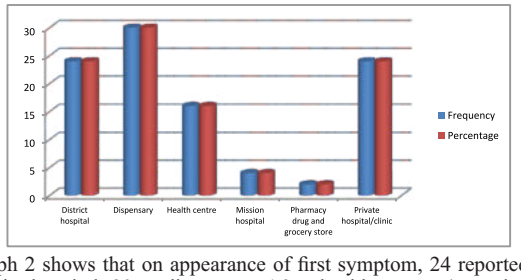
## Tables and graphs

### Graph 1. Reason for stopping TB treatment



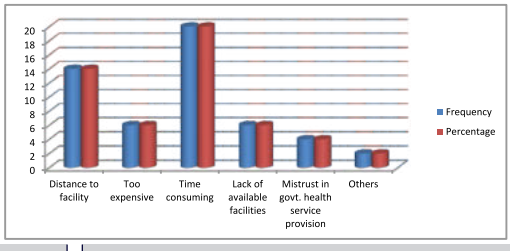

Graph 1 shows that reason for stopping treatment was lack of money in 6, drug side effects in 6, moved to other place in 2 and other causes in 2 patients.

### Graph 2 First point of contact, when patient had symptoms.



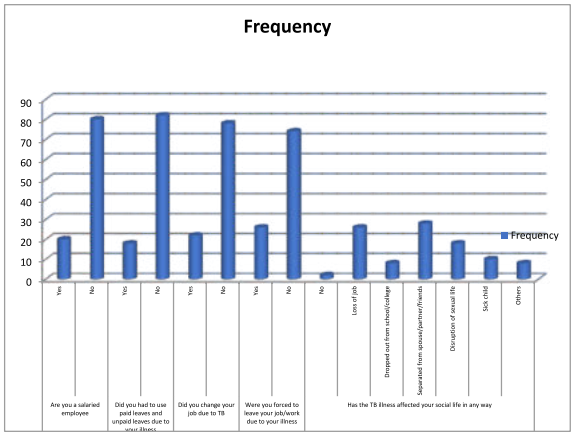

Graph 2 shows that on appearance of first symptom, 24 reported to district hospital, 30 to dispensary, 16 to health centre, 4 to mission hospital, 2 to pharmacy drug and grocery store and 24 to private hospital/clinic.

### Graph 3: Reason for not choosing government facility.



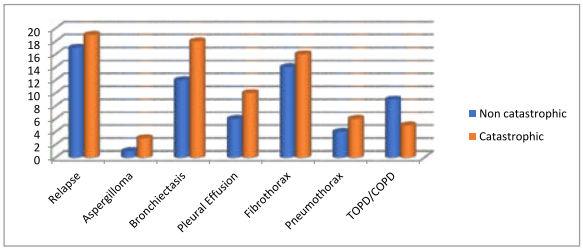

Graph 3 shows that reason for not obtaining health facility was distance to facility in 14, too expensive in 6, time consuming in 20, lack of available facilities in 6, mistrust in govt. health service provision in 4 and others in 2 patients.

### Graph 4 Frequency graph of social parameters




Graph 4 shows that 20 were salaried person, 18 had to use paid leaves and unpaid leaves due to your illness, 22 changed job due to TB, 26 were forced to leave your job/work due to your illness, 28 got separated from spouse/partner/friends, 18 had disruption of sexual life, 10 had sick child due to TB.

### Graph5: Treatment complications




Graph 5 shows that common complications were relapse seen 17 in non- catastrophic and 19 in catastrophic, aspergilloma 1 in non-catastrophic and 3 in catastrophic, bronchiectasis 12 in non-catastrophic and 18 in catastrophic, pleural effusion 6 in non-catastrophic and 10 in catastrophic, fibrothorax 14 in non- catastrophic and 16 in catastrophic, pneumothorax 4 in non- catastrophic and 6 in catastrophic and TOPD/COPD 9 in non- catastrophic and 5 in catastrophic.

### Table 1: Descriptive statistics

| Descriptive statistics | Mean | SD |
|---|---|---|
| Prediagnostic/diagnostic costs | 2738.2000 | 2519.18593 |
| Total Costs during Treatment | 5072.0000 | 6857.15847 |
| Guardian costs | 1604.0000 | 1653.33578 |
| Hospitalization Costs | 5928.5714 | 8651.32133 |
| Other Costs/Food supplements per month | 658.0000 | 795.21041 |
| Other costs/ Food supplement per year | 7896.0000 | 9542.52492 |
| Additional costs due to treatment for comorbid conditions | 551.0417 | 409.04119 |
| Annual expenditure on Comorbid conditions/Complications | 6180.0000 | 5068.62004 |
| Additional costs due to TB medications or complications due to TB per month | 724.8000 | 854.95405 |
| Additional costs due to complications Annually | 8697.6000 | 10259.44858 |
| How much received in reimbersement? | 6807.6923 | 8816.29165 |
| How much did you earn from the sale of your property | 25454.5455 | 57140.36791 |
| What was your estimated personal take home earning per month before TB illness | 11020.0000 | 9571.61207 |
| What is your income now | 5300.0000 | 6849.75853 |

| | | |
|---|---|---|
| How much was average household income per month before TB illness | 22860.0000 | 7787.60995 |
| How much is the average income of household per month now? | 17460.0000 | 8662.49317 |
| Annual Income | 209320.0000 | 104179.80572 |
| Total costs for TB treatment | 29316.6000 | 22762.92632 |
| 20% of annual income | 41864.0000 | 20835.96114 |

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