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Original Research Article

Estimation of the burden of catastrophic costs among the TB affected families of West Bengal, India: a secondary analysis of the sub-national certification survey data

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ABSTRACT

Background: Reducing catastrophic costs due to TB is one of the major targets of TB elimination, but there is little data available in India. A sub-national certification (SNC) survey was conducted in 105 clusters of 13 revenue districts of West Bengal. The purpose of this study was to calculate the catastrophic cost and its associations using the SNC data of West Bengal.
Methods: A cross-sectional study was conducted using the secondary data collected through SNC survey during December-2022-January-2023. 483 participants having history of TB were included in the study.
Results: 26.1% families were found to be affected with catastrophic cost due to TB. The mean annual family income was 691 USD (SD=806). Mean total cost incurred due to TB was 149 USD (SD=1208) including out of pocket of expenditure of 91 USD (SD=1147) and indirect costs of 58 USD (SD=200). No association of catastrophic cost was found with age, gender, religion, socio-clinical vulnerability or cash benefit received status. Those who were labourers, clinically diagnosed, diagnosed at private facilities, treatment duration more than six months and belonging to family below poverty line were found to be independently associated with higher being odds of affected with catastrophic costs.
Conclusions: Despite free medicine and free diagnostics many families are still facing catastrophic costs due to TB. Cash benefits should be prioritized towards most impoverished sector of the society. The National TB Elimination Program should also strategize to reduce indirect costs due to wage loss and productivity loss.

Keywords: Associations of catastrophic cost, Catastrophic cost due to tuberculosis, Out of pocket expenditure, Sub national certification, TB elimination

INTRODUCTION

In 2015, the United Nations (UN) Sustainable Development Goals (SDGs) were adopted, which are fully aligned with the WHO End TB Strategy. The SDGs have set the target of ending the TB epidemic by 2030.[1,2] All member states have a target to achieve an 80% reduction in the TB incidence rate by 2030 (compared with the 2015 baseline); 90% reduction in TB deaths by 2030 (compared with 2015); and 100% TB-affected families protected from facing catastrophic costs due to the disease from 2020 onwards.

Catastrophic costs are defined as the total direct and indirect costs that reach or exceed 20% of the TB patient's household's annual income. Direct costs represent either the medical cost (consultation fees, diagnostic tests, and treatment) or nonmedical cost (transportation, accommodation, and increased food needs). Indirect costs include lost wages due to unemployment, time spent away from work, and associated loss of productivity.[3,4]

Despite progress, the South East Asia Region (SEAR) including has missed the 2020 End TB milestones of a 35% decline in TB deaths, a 20% reduction in TB incidence rates as compared to 2015 baselines, and zero catastrophic costs among TB-affected families.[3] Incidence and mortality data is available for most of the countries but there is absolute dearth in catastrophic cost estimation data.[5] Catastrophic costs survey has been conducted in a limited (Myanmar and Timor Leste completed, Thailand and Indonesia- ongoing) number of countries in the SEAR. But India is lacking any recent information about the status of catastrophic cost.

In India, there is a wide variation in TB burden across the country. The efforts toward ending TB also vary across states/union territories (UTs) and districts of India. It is, therefore, crucial to monitor the progress towards the elimination goal at the subnational level. India has decided to incentivise states/UTs/districts by awarding Sub-National Certification (SNC) for their progress towards TB-free status.[6,7] The verification process included a community-based survey to collect data for estimation of TB incidence by three methods: (1) through a community-based survey (direct method), (2) by correcting the notification rate for under-reporting of cases in the notification system (indirect method) and (3) using drug sales and utilisation data.[6] Data related to Costs due to TB and Family income was also collected during this SNC survey. So, we have seen an opportunity estimate the catastrophic cost using the survey data.

As a part of the sub-national certification (SNC) survey in 2022-2023, 105 clusters (revenue village) from 13 revenue districts of West Bengal were randomly selected by the ICMR. The purpose of this study was to calculate the catastrophic cost and its associations using the SNC data of West Bengal. This study analysed the data from the state of West Bengal, which is a larger state with high burden of TB, so the study findings might be generalized to the whole population of India.

METHODS

Study design

We conducted an observational study. A secondary data analysis was performed on the data obtained through SNC survey in West Bengal in 2022-2023. Data downloaded from WHO's district level annual survey (DLAS) portal.[8,9]

Study setting

Study setting is West Bengal, which is a larger state at the eastern side of India. West Bengal is the home of more than 100 million people. The state is socio-culturally diverse, having three international borders with Nepal, Bhutan and Bangladesh. This is the only state in India, that has both the Himalayas in the north and the Bay of Bengal (part of the Indian Ocean) in the south, with plains and plateaus in between.

Study population and sample size

All consented household member interviewed during SNC survey 2022 was included as the study population. Sampling frame was TB patients with completed treatment (past episode of TB anytime in life) where there are not anymore chances of direct expenditure due to TB. We calculated sample size using CDC's web-based sample size calculator- OpenEpi.[10] Considering expected proportion of TB affected families burdened with catastrophic cost is 25% and with 5% absolute precision, 212 participants with history of TB needed to be randomly selected.[11] We have included all 483 identified past TB patients during the SNC survey 2022-2023 in the 13 revenue districts of West Bengal.

Study period

The SNC survey conducted during November 2022-February 2023. Past TB patients were considered who were with anti-TB treatment in between November 2021-October 2022. So during the SNC survey all the past TB patients have had completed their TB treatment.

Data collection and curation

Basic demographic details, details of TB episodes and details of cost incurred due to TB was extracted from downloaded data from WHO-India's DLAS web portal. The data was curated and variable categories were coded using Stata 14.2 (StataCorp LP, College Station, TX, USA). Amount of direct cash benefit paid to the patients collected from the Nikshay portal of Govt of India.[12] Nikshay portal is the web-based, case-based TB surveillance system in India.[13]

Operational definitions used in the study[12,14-17]

Direct costs due to TB

It includes expenses directly incurred by patients and their families for medical care, such as medication, investigations, and consultations, as well as non-medical costs like transportation and food.

Out of pocket expenditure (OOP)

It refers the direct costs incurred by patients and their families for TB treatment, including medical expenses, transportation that are not covered by insurance or other forms of financial assistance.

So, OOP = Direct costs - amount reimbursed/paid back

Indirect cost due to TB

It refers to financial loss due to wage loss, time loss and loss of productivity due to illness.

Total cost due to TB

It refers to the entire financial burden faced by a household due to tuberculosis, encompassing both direct medical and non-medical expenses adjusting for any reimbursement, as well as adding the indirect costs like lost income.

So, Total cost = (direct costs-reimbursements) + indirect cost = OOP + indirect costs

Data analysis

Stata 14.2 was also used for statistical analysis. After normality testing, the median and interquartile range (IQR) was calculated for the quantitative variables. The Proportions of different sociodemographic categories and measures of bivariate statistical associations with p values calculated with Chi-square test. Before calculation of the strength of association, the participants were categorized according to their sociodemographic and clinical parameters.

Unadjusted odds ratio (OR) and Adjusted (adjusted with other independent factors) Odds Ratio (aOR) was calculated using a negative binomial regression model and a logistic regression model respectively to assess the independent associations. 95% confidence interval (95% CI) obtained from the models. A p value of <0.05 was taken as statistically significant.

RESULTS

26.1% (CI=22.2%-30.2%) TB patient's families were affected with catastrophic cost due to TB.

Descriptive statistics

Mean age of the participants (TB patients) was 47 years (SD=15); Mean treatment duration was 7 months (SD=4). Mean annual family income was 691 USD (SD=808). Mean direct cost (diagnosis + treatment + non-medical) due to TB was 106 USD (SD=1146) whereas, mean cash benefit received was 15 USD (SD=19). Mean out of pocket expenditure was 91 USD (1147) whereas mean indirect cost (wage loss) was 58 USD (SD=200). Mean total cost incurred due to TB was 149 USD (SD=1208) (Table 1).

Table 1: Quantitative variables of the participants (past TB patients) of the catastrophic cost estimation study in West Bengal, during the SNC survey 2022-2023, N=483.

Variables	Mean	SD
Age in years	47	15
Treatment duration in month	7	4
Annual family income (USD*)	691	808
Cost of TB diagnosis (USD*)	15	66
Cost of TB Treatment (USD*)	76	1113
Non-medical cost due to TB (USD*)	14	65
Direct cost due to TB (USD*)	106	1146
DBT money received (USD*)	15	19
Mean out of pocket expenditure (USD*)	91	1147
Indirect cost incurred due to TB (USD*)	58	200
Total cost incurred due to TB (USD*)	149	1208

*Calculated considering the currency exchange rate as on 01/01/2023 (1 USD = 82.7433 INR).[18]
Abbreviations: SNC= Sub National Certification; SD= Standard deviation; USD=United States Dollar, INR= Indian Rupee; TB= tuberculosis; DBT= direct benefit transfer.

Socio-economic and clinical profile of the TB patients

Among all participants 73.1% were from economically productive age group (15-59 years) and 71.4% were male. Major religion was Hinduism (88.2%). Most the patients were either labourer (33.8%) or non-working group (37.5%) comprises of homemaker, retired person, student and unemployed and 26.1% families belonged to below poverty level. 30.9% TB patients were already vulnerable for TB (clinically, socially or occupationally) and 15.7% TB patients were clinically diagnosed (not bacteriologically confirmed). Treatment duration was more than six months for 24.9% patients and 6.2% patients had taken TB treatment exclusively from private healthcare facilities. 59.2% TB patients received cash benefits.

Table 2: Socio-economic and clinical profile of the participants (past TB patients) of the catastrophic cost estimation study in West Bengal, during SNC survey 2022-2023.

Variables	Total N (%*) (n=483)	No. catastrophic cost N (%*) (n=357)	Catastrophic cost N (%*) (n=126)	P value
Age group (years)				
0-14	6 (1.2)	5 (1.4)	1 (0.8)	0.045
15-29	69 (14.3)	57 (16.0)	12 (9.5)	
30-59	284 (58.8)	214 (59.9)	70 (55.6)	
60 and above	124 (25.7)	81 (22.7)	43 (34.1)	
Gender				
Male	345 (71.4)	251 (70.3)	94 (74.6)	0.359
Female	138 (28.6)	106 (29.7)	32 (25.4)	
Religion				
Hindu	426 (88.2)	315 (88.2)	111 (88.1)	0.967
Muslim and other minorities	57 (11.8)	42 (11.8)	15 (11.9)	
Occupation				
Unemployed/retired	181 (37.5)	143 (40.1)	38 (30.2)	0.003
Labourer	163 (33.8)	103 (28.9)	60 (47.6)	
Farmer	88 (18.2)	70 (19.6)	18 (14.3)	
Business	20 (4.1)	18 (5.0)	2 (1.6)	
Salaried	31 (6.4)	23 (6.4)	8 (6.3)	
Income group[$]				
APL	357 (73.9)	294 (82.4)	63 (50.0)	0.000
BPL	126 (26.1)	63 (17.6)	63 (50.0)	
NPY-DBT status				
DBT received	286 (59.2)	215 (60.2)	71 (56.3)	0.447
DBT not received	197 (40.8)	142 (39.8)	55 (43.7)	
Risk group				
Vulnerable[#]	149 (30.9)	84 (23.5)	65 (51.6)	0.000
Not vulnerable	334 (69.1)	273 (76.5)	61 (48.4)	
Basis of diagnosis				
Clinical	76 (15.7)	45 (12.6)	31 (24.6)	0.001
Microbiological	407 (84.3)	312 (87.4)	95 (75.4)	
TB treatment duration				
Six months	362 (75.1)	297 (83.2)	66 (52.4)	0.000
More than six months	120 (24.9)	60 (16.8)	60 (47.6)	
Type of healthcare facility				
Private	30 (6.2)	6 (1.7)	24 (19.1)	0.000
Public	453 (93.8)	351 (98.3)	102 (80.9)	

Notes: *column percentage (within the category); [$]Annual family income of INR 27000 (326 USD) or less is considered as BPL.[19] [#]Clinically, socially, and occupationally vulnerable populations who are at higher risk for getting TB.[20] Proportions and p-value calculated with Chi square test. Abbreviations: SNC= sub national certification; APL= above poverty line, BPL= below poverty line TB= Tuberculosis; NPY= Nikshay Poshan Yojna; DBT= Direct Benefit Transfer

Whereas, among the TB patients affected with catastrophic cost 65.5% were from economically productive age group and 74.6% were male. Major religion was Hinduism (88.1%). Most the patients were either labourer (47.6%) or non-working group (30.2%) and 50% TB patient's families belonged to below poverty level. 51.6% TB patients were already vulnerable for TB and 24.6% TB patients were clinically diagnosed. Treatment duration was more than six months for 52.4% patients and 19.1% patients had taken TB treatment exclusively from the private healthcare facilities. 56.3% TB patients received cash benefits (Table 2).

Socio demographic association of catastrophic cost among the TB patients

The logistic regression model identified that the labourers [aOR 2.7; CI (1.3-5.8)] those who belong to below poverty line [aOR 5.5; CI (3.1-9.8)], patients who were clinically diagnosed [aOR 2.5; CI (1.3-4.9)], where treatment duration was more than six months [aOR 2.4;

CI (1.4-4.3)] and patients diagnosed at private health facility [aOR 10.6; CI (3.8-29.8)] were independently associated with catastrophic cost due to TB.

Table 3: Socio Demographic association of catastrophic cost among the participants (past TB patients) of the catastrophic cost estimation study in West Bengal, during SNC survey 2022- 2023, n=483, N=133.

Variables	Total, N	Catastrophic Cost, n (%#)	OR (95% CI)	aOR (95% CI)
Age group (years)				
0-14	6	2 (33.3)	1 (0.1-8.9)	1 (0.1-13.1)
15-29	69	13 (18.8)	1 (base)	1 (base)
30-59	284	72 (25.4)	1.6 (0.8-3.1)	1.7 (0.7-3.7)
60 and above	124	46 (37.1)	2.5 (1.2-5.2)	2.3 (0.9-5.4)
Gender				
Male	345	98 (28.4)	1.2 (0.8-2)	1.1 (0.5-2.2)
Female	138	35 (25.4)	1 (base)	1 (base)
Religion				
Hindu	426	117 (27.5)	1 (base)	1 (base)
Muslim and other minorities	57	16 (28.1)	1 (0.5-1.9)	1.5 (0.7-3.1)
Occupation				
Unemployed/retired	181	42 (23.2)	1 (0.6-1.9)	1.5 (0.6-3.7)
Labourer	163	61 (37.4)	2.3 (1.2-4.2)	2.7 (1.3-5.8)
Farmer	88	20 (22.7)	1 (base)	1 (base)
Business	20	2 (10)	0.4 (0.1-2)	1.5 (0.3-7.8)
Salaried	31	8 (25.8)	1.4 (0.5-3.5)	2.8 (0.9-8.6)
Income group				
APL	357	68 (19)	1 (base)	1 (base)
BPL	126	65 (51.6)	4.7 (3-7.3)	5.5 (3.1-9.8)
NPY-DBT status				
DBT received	286	71 (24.8)	1 (base)	1 (base)
DBT not received	197	55 (27.9)	1.2 (0.8-1.8)	1.1 (0.7-1.9)
Risk group				
Vulnerable	149	65 (43.6)	3.5 (2.3-5.3)	1.7 (0.9-3)
Not vulnerable	334	68 (20.4)	1 (base)	1 (base)
Basis of diagnosis				
Clinical	76	35 (46.1)	2.3 (1.4-3.8)	2.5 (1.3-4.9)
Microbiological	407	98 (24.1)	1 (base)	1 (base)
TB treatment duration				
Six months	362	71 (19.6)	1 (base)	1 (base)
More than six months	120	62 (51.7)	4.6 (2.9-7.1)	2.4 (1.4-4.3)
Type of healthcare facility				
Private	30	24 (80)	13.8 (5.5-34.6)	10.6 (3.8-29.8)
Public	453	109 (24.1)	1 (base)	1 (base)

Notes: # row percentages; OR with CI calculated using generalized linear models for binomial family and aOR with CI calculated using logistic regression model. OR= Odds ratio, aOR= adjusted odds ratio (adjusted with other independent variables), CI= 95% confidence interval; SNC= Sub National Certification, APL= above poverty line, BPL= below poverty line; TB= tuberculosis; NPY= Nikshay Poshan Yojna; DBT= direct benefit transfer.

No significant association of catastrophic cost is found with age, gender, religion, status of cash benefit received or vulnerability status of the TB patients (Table 3).

Among the TB patients who belong to APL family, 60.2% (215/357) received NPY cash benefit whereas among those who belong to BPL family, 56.4% (71/126) received the cash benefit.

DISCUSSION

With best our knowledge, this is the only such study in West Bengal and one of the first studies in India to assess the proportion of TB affected families burdened with

catastrophic cost due to TB and the associations especially the role of NPY-DBT.

Discussion on key findings

The findings from our study represent the scenario of a large state in India and are relevant from the policy perspective also.

First, 26.1% families were affected with catastrophic cost due to TB which is far behind the goal of "zero catastrophic cost". Studies in other countries in SEAR revealed wide range of catastrophic cost affected family, starting from 80% at Timor Leste to 20% at Thailand.[3] An Indian study reported that 31% of TB-affected households of an Indian metro city still experienced catastrophic costs.[18]

Second, the median annual income of TB affected families is 691 USD. The annual family income of the study participants was significantly lesser than the mean household income of India in 2022 (3336 USD).[19] Once again, it is evident that TB strikes the most impoverished families of our society.

Third, the mean total cost incurred due to TB was 149 USD which is lesser than that of our neighbouring country Myanmar (USD 649 -2492).[3] Median indirect cost was 58 USD which is 39% of total cost due to TB. The indirect cost might be much higher as the study considered only wage loss and didn't consider financial loss due to time loss or productivity loss due to TB. The National Tuberculosis Elimination Program (NTEP) has several policies to minimize the direct cost by providing free doctors consultation, free sample collection and transportation system, free diagnostics, free medicine, travel allowance etc. But there are no robust policies for compensation of wage loss or time loss or productivity loss. There is no stringent guideline when the persons with TB can resume their employment. Many workers especially those who are working at unorganized sector (e.g., domestic help, contractual private job, daily labourer etc.) often had to remain jobless throughout the entire treatment period. Some even loses their jobs due to TB. This is the time when Government should enforce strict law to minimize discrimination against TB patients in the work fields.

Fourth, there was no significant association between catastrophic cost and NPY-DBT. Which means the cash benefit failed to reduce catastrophic cost. This is mainly because all benefits are not paid to all beneficiaries and there was no prioritization whom to provide the benefits. The study revealed that among those who belong to APL family, 60.2% received NPY cash benefit whereas among those who belong to BPL family, 56.4% received the cash benefit. The program should now prioritize the benefits based on the economic status of the family of the TB patients.

Fifth, the study also identified that those who are labourer, who belong to BPL family, those who were clinically diagnosed, where treatment duration was higher and those who had taken care from Private healthcare facility were more likely to be burdened with catastrophic cost. The program should take extra care for the most impoverished sections of the society. There is a dire need of systematic evaluation of socio-economic status of all TB patients. Cost reimbursement or linkages with free services for the private sector patients can be a way-out to reduce out of pocket expenditure for the TB affected families.

This study is the first such study in West Bengal and one of the first studies in India to assess the catastrophic cost due to TB. The study had a relatively large sample size and reflects the scenario of the whole state of West Bengal. The careful data curation and the robust study design of SNC survey, appropriate measures for the strength of association is also a strength of the study.[6] We adhered to 'reporting guidelines for implementation and operational research' for reporting of the study's findings.[20]

Despite our sincere efforts there are few weaknesses of our study. We could not consider the presence of existing illness/co-morbidities, nutritional status, travel distance from home to health centre, number of family members, educational qualifications while adjusting the odds ratio. The study also couldn't consider the indirect financial loss due to time or productivity loss any type of cost after completion of TB treatment.

CONCLUSION

SNC survey is a good opportunity to estimate catastrophic cost nationwide. Despite free medicine and free diagnostic many families are still facing catastrophic cost due to TB. The cash benefit paid under NPY has failed to reduce catastrophic cost. Time has come to prioritize the provision of DBT and financial benefits based on socio-economic status of the TB patients.

Recommendations

The National TB Elimination Program should now introduce the process of systematic evaluation of socio-economic status of all TB patients and adopt a differentiated financial protection approach to reach the target of 'zero' catastrophic cost.

Systematic engagement of private sector followed by cost reimbursement and linkages with free services for the private sector patients can be a way-out to reduce out of pocket expenditure for the TB affected family.

The NPY and other DBTs should be prioritized towards most impoverished sector of the society.

The program should also strategize to reduce indirect costs due to wage loss & productivity loss. Provision of paid leave to TB affected person and strong legislation against lay off TB patient from job can be a way forward.

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