



# Catastrophic costs in tuberculosis patients in Brazil: a study in five capitals

*Custos catastróficos em pacientes com tuberculose no Brasil: estudo em cinco capitais*

*Costos catastróficos en pacientes con tuberculosis en Brasil: un estudio en cinco capitales*

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## ABSTRACT

**Objective:** to assess the home economics impact of illness from Tuberculosis in Brazil. **Method:** multicenter cross-sectional research from 2016 to 2018, in five capitals of Brazil, in patients diagnosed with tuberculosis. The total costs were the sum of the direct and indirect costs incurred before and during diagnosis and treatment. Logistic regression was used to study determinants of catastrophic costs. Poverty was measured as daily household income per capita < U\$ 5.5. **Results:** 361 patients were enrolled in the study. The extrapolation cost was R\$ 3,664.47 (SD: R\$ 2,667.67) and the total extrapolation cost was R\$ 22,291.82 (SD: R\$ 16,259.50). Overall, 29% of study participants were characterized as poor before tuberculosis, and 39% afterwards. On average, income declined by 11% among participants and 41% had catastrophic costs. The statistically significant determinants of experiencing catastrophic costs were: participant being the head of the family; living in poverty before tuberculosis; unemployment and interruption of work during treatment ( $p < 0.05$ ). **Conclusion and implications for practice:** although treatment is financed by the government, tuberculosis continues to cause catastrophic costs and decreased of income for many families in Brazil.

**Keywords:** Tuberculosis; Therapeutics; Costs and Cost Analysis; Cross-Sectional Studies; Brazil.

## RESUMO

**Objetivo:** avaliar o impacto econômico domiciliar do adoecimento pela tuberculose no Brasil. **Método:** pesquisa transversal multicêntrica de 2016 a 2018, em cinco capitais do Brasil, em pacientes diagnosticados com tuberculose. Os custos totais foram a soma dos custos diretos e indiretos incorridos antes e durante o diagnóstico e tratamento. A regressão logística foi utilizada para estudar determinantes de custos catastróficos. A pobreza foi medida como renda familiar per capita diária < U\$ 5,5. **Resultados:** trezentos e sessenta e um pacientes foram inscritos no estudo. O custo extrapolado foi de R\$3.664,47 (DP: R\$ 2.667,67) e o custo total de extrapolação foi de R\$22.291,82 (DP: R\$ 16.259,50). No geral, 29% dos participantes do estudo foram caracterizados como pobres antes da tuberculose, e 39% depois. Em média, a renda diminuiu em 11% dos participantes e 41% tiveram custos catastróficos. Os determinantes estatisticamente significativos de experimentar custos catastróficos foram: participante ser o chefe da família, vivendo na pobreza antes da tuberculose, desemprego e interrupção do trabalho durante o tratamento ( $p < 0,05$ ). **Conclusão e implicações para a prática:** embora o tratamento seja financiado pelo governo, a tuberculose continua resultando em custos catastróficos e diminuição da renda para muitas famílias no Brasil.

**Palavras-chave:** Tuberculose; Terapêutica; Custos e Análise de Custo; Estudos Transversais; Brasil.

## RESUMEN

**Objetivo:** evaluar el impacto económico domiciliario de enfermarse por tuberculosis en Brasil. **Método:** Investigación multicéntrica transversal de 2016 a 2018, en cinco capitales de Brasil, en pacientes diagnosticados con tuberculosis. Los costos totales fueron la suma de los costos directos e indirectos incurridos antes y durante el diagnóstico y el tratamiento. Se utilizó la regresión logística para estudiar los determinantes de los costos catastróficos. La pobreza se midió como un ingreso familiar diario per cápita < U\$ 5,5. **Resultados:** se inscribieron 361 pacientes en el estudio. El costo de extrapolación fue de R\$ 3.664,47 (DE: R\$ 2.667,67) y el costo total de extrapolación fue R\$ 22.291,82 (DE: R\$ 16.259,50). En general, el 29% de los participantes se caracterizaron como pobres antes de la tuberculosis y el 39%, después. En promedio, los ingresos disminuyeron en 11% de los participantes y el 41% tuvo costos catastróficos. Determinantes estadísticos de costos catastróficos: participante ser cabeza de familia; vivir en pobreza antes de la tuberculosis; desempleo; interrupción del trabajo durante el tratamiento ( $p < 0,05$ ). **Conclusión e implicaciones para la práctica:** aunque el tratamiento es financiado por el gobierno, la tuberculosis sigue teniendo costos catastróficos y una disminución de los ingresos para muchas familias en Brasil.

**Palabras clave:** Tuberculosis; Terapêutica; Custos y Análisis de Costo; Estudios Transversales; Brasil.

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## INTRODUCTION

Brazil, to prevent households affected by Tuberculosis (TB) from experiencing financial difficulties, works with two important strategies for the health and income of the population<sup>1-2</sup>. However, TB remains associated with poverty in Brazil and worldwide<sup>3-8</sup>. In 2016, it is estimated that 1.6 million deaths from TB and 11.4 million new cases of TB occurred in developing countries.<sup>9</sup> Spending on prevention, diagnosis and treatment reached US\$ 6.6 billion globally in 2015, against \$6.2 billion in 2014<sup>10</sup>. The 2019 updated estimates for funding prevention, diagnosis and treatment in total for 2018-2022 are \$60 billion (an average of \$12 billion per year) for the developing countries<sup>11</sup>.

Despite free treatment, people with TB experience high costs that can sometimes lead to reduced income<sup>5-6,12</sup>. The total costs faced by people with TB are made up of direct expenses with medication, hospitalization, transportation and food, as well as indirect costs from the loss of income related to inability to work during illness due to time spent in care, stigma and discrimination. Both direct and indirect costs are incurred before and after the diagnosis of TB, and may be incurred by patients, as well as other family members who provide care and support<sup>13</sup>. In addition to direct or indirect costs, families affected by TB may also endure costs of having to make use of preventive savings and loans from friends and relatives<sup>13</sup>.

After the launch of the Commission on Social Determinants of Health in 2008, the World Health Organization (WHO) intensified its focus on the social determinants of health<sup>14</sup>. This is reflected in its "End TB" strategy that endorses social protection, the alleviation of poverty and actions on other determinants of TB. One of the indicators for progress in the "End TB" strategy is the reduction in the number of families affected by the total catastrophic costs due to TB by 2020<sup>15</sup>. The WHO established the total catastrophic costs due to TB as total costs incurred by families related to TB in excess of 20% of the annual family income<sup>13</sup>.

National representative studies characterizing TB-related household costs have been conducted in several countries, including Vietnam, Uganda, Thailand, Ghana and Indonesia<sup>3-6,12,16</sup>. In Brazil, studies have already investigated the costs of TB patients, however, these were focused only at one city or one state<sup>17-19</sup>. In this sense, the study aimed to assess the occurrence of catastrophic cost due to TB in five capitals, one in each region of Brazil.

## METHODS

A multicenter cross-sectional study was carried out between June 2016 and June 2018 in 14 health units located in five capitals, one in each region of Brazil (Manaus, Recife, Vitória, Campo Grande and Porto Alegre).

The study setting was Brazil, which is among the 20 countries with a high burden of TB and, in 2019, reported 73,864 cases of incident TB<sup>20</sup>. Factors such as population density, race and poverty index are determinants for high rates of TB in the country<sup>21</sup>. In Brazil, TB treatment is integrated into the government-funded

universal health system that provides all diagnostic, antimicrobial and, when necessary, hospital services free of charge<sup>20</sup>.

Data were obtained through a cross-culturally adapted questionnaire from the patient cost manual proposed by the WHO<sup>13,22-23</sup>. The final questionnaire collected data on participants' socioeconomic information (e.g., income), treatment expenses before the diagnosis of TB, with the diagnosis and during the treatment of TB, as well as the time spent in the search for or access to TB care<sup>22-23</sup>. The interviews were carried out individually, in the selected units.

Inclusion criteria for sample composition were: individuals diagnosed with TB aged 18 years or older, for at least 14 days with sensitive treatment for the Basic Scheme (rifampicin, isoniazid, pyrazinamide and ethambutol for 2 months and rifampicin and isoniazid for more than 4 months) and who reported family income before and after TB.

To calculate the sample, we used the incidence rate of the disease considered in 2012, according to data from the *Sistema de Informação de Agravos de Notificação* (Notifiable Diseases Information System, in free translation) updated in December 2013. A sample size of 330 was necessary to estimate the proportion of costs and analysis of catastrophic costs among the population studied, with an accuracy of 5%, assuming a 20% loss, 40% proportion of catastrophic costs and a design effect of 1.7.

Survey participants were sampled for the five capitals selected in proportion to the notification of TB in each state capital. Anticipating possible losses during cost data collection, the sample was increased by 10%, obtaining a sample size of 363 participants, and data collection was carried out with 361 participants. Of the 361 eligible patients, 11 were excluded for not reporting family income before and after TB, constituting a sample of 350 patients.

For direct cost analysis related to TB, we used pre-diagnosis and treatment costs. Direct pre-diagnosis costs included self-reported expenses for consultations, tests and medications deducted any insurance reimbursement, as well as travel, food and accommodation to access health services. Direct costs during treatment included expenses for accessing Directly Observed Treatment (DOT); picking up of anti-TB drugs; follow-up tests; hospitalization; and the purchase of special foods.

The indirect cost to the patient due to incapacity for work was the estimate of the self-reported monthly income before TB multiplied by the number of months that participants reported stopping work due to illness.

Analysis of total costs related to TB was carried out as recommended by WHO and costs were collected for a period of one month. This approach requires calculations to estimate total costs. At first, participants' self-reported costs were extrapolated to the remainder of the current treatment phase (intensive phase: 2 months; maintenance phase: 4/6 months). Next, costs for the other phase of treatment were imputed using the average reported cost of survey participants interviewed in that phase. For more details, see "WHO's Tuberculosis Patient Cost Surveys: A Handbook"<sup>13</sup>.

Coping costs were the sum of borrowed money multiplied by the reported interest rate, plus the difference in price and value of the properties sold.

For the analysis of financial difficulties related to TB we measured costs and financial difficulties in two ways, catastrophic costs and income decrease. To calculate the catastrophic costs due to TB, we used the sum of the total direct and indirect costs divided by the amount of annual family income before falling ill with TB. We classify participants with total costs  $\geq 20\%$  of annual household income as having a catastrophic cost. To calculate the decrease in income due to TB, we subtracted the self-reported monthly family income before and after the disease. For the characterization of poverty, we classified families as poor and not poor before and after TB using the World Bank family income limit of US\$5.5 per day, recommended for developed and underdeveloped countries such as Brazil<sup>24</sup>.

Statistical analysis was performed using STATA 14.0. We summarize participant costs, socioeconomic characteristics and the number of participants experiencing financial difficulties. The chi-square test ( $\chi^2$ ) was used to compare discrete data, and the analysis of variance test (ANOVA) was used to compare continuous data. The kappa coefficient of agreement and McNemar test were used to test consistency in reporting poverty status before and after TB. Logistic regression was used to investigate risk factors for the catastrophic cost experience. Hypothetical risk factors associated with outcomes at  $p$ -value ( $p < 0.2$ ) were included in the multivariate analysis. We tested the sensitivity of catastrophic costs by using three other cost thresholds  $\geq 10\%$ ,  $\geq 15\%$  and  $\geq 25\%$  of annual household income.

The project was approved by the research ethics committee of the *Centro de Ciências da Saúde* /Health Sciences Center of the Universidade Federal do Espírito Santo (CEP/UFES) (1,856,319/2016), and by committees from each of the capitals under study. All participants signed an informed consent form.

## RESULTS

**Descriptive characteristics.** Of the 350 study participants, 226 (65%) were male, and in informal work 211 (60%). Most did not have a private health plan (277 / 79%) (Table 1).

**Costs related to TB.** The average cost of extrapolation was R\$ 3,664.47 (SD: R\$ 2,667.67). The average total cost of extrapolation was R\$ 22,291.82 (SD: R\$ 16,259.50) (Table 2).

**Financial difficulties related to TB.** Approximately 41% of the sample experienced catastrophic costs due to TB  $\geq 20\%$ . Forty participants (11%) went from not poor before TB to poor after TB. Kappa statistics and McNemar's test were statistically significant ( $p < 0.001$ ) (Table 3).

**Determinants of catastrophic costs due to TB.** In the multivariate logistic regression, the following four determinants were significantly associated with the experience of catastrophic costs: patient head of the family (aOR: 2.01 (1.23-3.28);  $P = 0.005$ ), living in poverty before TB (aOR: 2.65 (1.22-5.76);  $P = 0.014$ ), current informal employment (aOR: 1.48 (1.13-1.94);  $P = 0.004$ ), and not work during illness (aOR: 1.72 (1.03-2.84);  $P = 0.035$ ) (Table 4).

**Sensitivity analysis.** Catastrophic cost thresholds of 10%, 15%, 20% and 25% were used and the participants who presented catastrophic cost in the respective thresholds were considered poor 85 (84%), 71 (70%), 61 (60%) and 44 (44%), respectively (Table 5).

## DISCUSSION

It was found that 145 (41%) of TB patients experienced catastrophic costs and there was an 11% increase in the probability of living in poverty during treatment compared to pre-illness. The main contributor to the total costs was indirect costs. Four determinants were associated with the experience of catastrophic costs: patient head of household, living in poverty before TB, current informal employment, and stopping to work during the illness.

The results of this study suggest that the economic impact of TB on patients and their families in Brazil remains severe<sup>25</sup>. This finding is consistent with previous studies in Brazil and worldwide. In 2005, it was found that families in Salvador, Brazil, committed about 33% of their family income to pay for the diagnosis and treatment of TB. Loss of income due to incapacity for work was the factor that most contributed to the economic burden of families with TB<sup>18</sup>. In 2010, another study in Brazil showed that the costs incurred by TB patients were high, especially for those on DOT and observed an increase in costs during the treatment phase for those on DOT, while self-administered treatment was associated with relatively higher costs during the pre-diagnosis phase<sup>17</sup>. In the present study, indicators of the patients' financial situation were the main determinants for catastrophic costs. These findings are consistent with previous studies and highlight the need for additional financial protection for families affected by TB<sup>16</sup>.

The strength of the study was that it sampled patients from each of the five regions of Brazil. The representativeness of the sample is confirmed by the similarity of the summary sociodemographic characteristics with the national registry of electronic TB Information System for Notifiable Diseases from 2014 to 2016<sup>26</sup>.

Although universal health coverage is available throughout Brazil, this study indicates that TB patients are still at risk of financial difficulties. This indicates that there is a need for government interventions to defray the costs related to TB. In Peru, a TB-specific socioeconomic intervention targeting poor families was accessible to this population and reduced their likelihood of experiencing catastrophic costs<sup>27</sup>. In Brazil, the adoption of government social protection for drug-resistant TB is associated with a reduced likelihood of facing financial difficulties<sup>28</sup>.

An economic modeling study in seven low- and middle-income countries indicates that cash transfers are likely to reduce the burden of TB costs for affected households<sup>29</sup>.

The costs that contributed to 145 families facing catastrophic costs during the diagnosis and treatment of TB were the direct costs of transportation, food and especially loss of income. This risk is greater in patients from poor families, as they are at greater risk of interruption of work and study and this may be related to more serious

**Table 1.** Characteristics of the study participants of the 5 regions of Brazil from June/2016 to July/2018 (n = 350).

| Variables  | Total    | Catastrophic cost |          | p-value |
|--|----------|-------------------|----------|---------|
|  |          | No (%)            | Yes (%)  |         |
| <b>Gender</b>                                    |          |                   |          |         |
| Male   | 226 (65) | 137 (60)          | 89 (39)  | 0.294   |
| Female   | 124 (35) | 68 (55)           | 56 (45)  |         |
| <b>Education</b>                                 |          |                   |          |         |
| Illiterate                                       | 19 (5)   | 10 (53)           | 9 (47)   | 0.260   |
| Elementary School                                | 154 (44) | 83 (54)           | 71 (46)  |         |
| High school                                      | 138 (40) | 85 (62)           | 53 (38)  |         |
| University education                             | 39 (11)  | 27 (69)           | 12 (31)  |         |
| <b>Age (years)</b>                               |          |                   |          |         |
| 18-40  | 165 (47) | 93 (56)           | 72 (44)  | 0.275   |
| > 40   | 182 (52) | 109 (60)          | 73 (40)  |         |
| Uninformed                                       | 3 (1)    | 3 (100)           | 0        |         |
| <b>Race</b>                                      |          |                   |          |         |
| White  | 91 (26)  | 56 (62)           | 35 (38)  | 0.622   |
| Black  | 55 (16)  | 31 (56)           | 24 (44)  |         |
| Yellow   | 7 (2)    | 3 (43)            | 4 (57)   |         |
| Brown  | 178 (50) | 107 (60)          | 71 (40)  |         |
| Indigenous                                       | 17 (5)   | 7 (41)            | 10 (59)  |         |
| Uninformed                                       | 2 (1)    | 1 (50)            | 1 (50)   |         |
| <b>Head of the family</b>                        |          |                   |          |         |
| Patient  | 162 (46) | 86 (53)           | 76 (47)  | 0.053   |
| Not patient                                      | 188 (54) | 119 (63)          | 69 (37)  |         |
| <b>Formal work</b>                               |          |                   |          |         |
| Yes  | 139 (40) | 97 (70)           | 42 (30)  | 0.001   |
| No   | 211 (60) | 108 (51)          | 103 (49) |         |
| <b>Stop working/studying due to tuberculosis</b> |          |                   |          |         |
| Yes  | 218 (63) | 116 (53)          | 102 (47) | 0.017   |
| No   | 126 (36) | 86 (68)           | 40 (32)  |         |
| Uninformed                                       | 6 (2)    | 3 (50)            | 3 (50)   |         |
| <b>Health plan</b>                               |          |                   |          |         |
| Yes  | 73 (21)  | 49 (67)           | 24 (33)  | 0.095   |
| No   | 277 (79) | 156 (56)          | 121 (44) |         |
| <b>Type of TB</b>                                |          |                   |          |         |
| Pulmonary  | 263 (75) | 161 (61)          | 102 (39) | 0.081   |
| Extrapulmonary                                   | 87 (25)  | 44 (51)           | 43 (49)  |         |
| <b>Treatment phase</b>                           |          |                   |          |         |
| Intensive  | 98 (28)  | 51 (52)           | 47 (48)  | 0.122   |
| Maintenance                                      | 252 (72) | 154 (61)          | 98 (39)  |         |
| <b>HIV</b>                                       |          |                   |          |         |
| Positive   | 60 (17)  | 33 (55)           | 27 (45)  | 0.377   |
| Negative   | 241 (69) | 139 (58)          | 102 (42) |         |

**Source:** Study database.

**Legend:** TB - tuberculosis / HIV - human immunodeficiency virus.

**Table 1.** Continued...

| Variables                        | Total            | Catastrophic cost |            | p-value |
|----------------------------------|------------------|-------------------|------------|---------|
|                                  |                  | No (%)            | Yes (%)    |         |
| Not tested/unknown               | 49 (14)          | 33 (67)           | 16 (33)    |         |
| <b>Hospitalization</b>           |                  |                   |            |         |
| Yes                              | 140 (40)         | 77 (55)           | 63 (45)    | 0.268   |
| No                               | 210 (60)         | 128 (61)          | 82 (39)    |         |
| <b>Previous treatment for TB</b> |                  |                   |            |         |
| Yes                              | 60 (17)          | 29 (48)           | 31 (52)    | 0.077   |
| No                               | 290 (83)         | 176 (61)          | 114 (39)   |         |
| <b>First care</b>                |                  |                   |            |         |
| Public hospital                  | 67 (19)          | 42 (63)           | 25 (37)    | 0.817   |
| Hospital or private clinic       | 22 (7)           | 14 (64)           | 8 (36)     |         |
| Basic Health Unit                | 247 (70)         | 141 (57)          | 106 (43)   |         |
| Others                           | 14 (4)           | 8 (57)            | 6 (43)     |         |
| <b>Comorbidities</b>             |                  |                   |            |         |
| Yes                              | 142 (41)         | 81 (57)           | 61 (43)    | 0.631   |
| No                               | 208 (59)         | 124 (60)          | 84 (40)    |         |
| <b>TOTAL</b>                     | <b>350 (100)</b> | <b>205</b>        | <b>145</b> |         |

Source: Study database.

Legend: TB - tuberculosis / HIV - human immunodeficiency virus.

**Table 2.** Distribution of costs related to Tuberculosis of participants from the 5 regions of Brazil in the period from June/2016 to July/2018 (n = 350).

| Costs                               | Average(R\$) | SD        | Min         | Max        |
|-------------------------------------|--------------|-----------|-------------|------------|
| Diagnostic and pre-diagnostic costs | 209.65       | 598.99    | (0 -        | 6.800.01)  |
| DOT costs                           | 5.85         | 34.62     | (0 -        | 460.98)    |
| Costs picking up medication         | 40.39        | 151.10    | (0 -        | 1.650.00)  |
| Consultation costs                  | 8.37         | 47.04     | (0 -        | 600.00)    |
| Hospitalization Costs               | 38.68        | 314.65    | (0 -        | 4,499.98)  |
| Food costs                          | 106.51       | 229.81    | (0 -        | 2,999.99)  |
| Treatment reimbursement             | 6.51         | 65.14     | (0 -        | 899.99)    |
| Direct patient costs                | 193.24       | 533.93    | (0 -        | 7,503.51)  |
| Indirect costs                      | 3,442.22     | 4,220.16  | (0 -        | 23,134.37) |
| Direct and indirect costs           | 3,634.79     | 4,304.72  | (0 -        | 23,138.43) |
| Extrapolation costs per month       | 3,664.47     | 2,667.67  | (534.14 -   | 16,599.97) |
| Total extrapolation costs           | 22,291.82    | 16,259.50 | (3,204.85 - | 99,599.95) |
| Coping costs                        | 339.54       | 2,508.84  | (0 -        | 35,000.00) |
| Monthly family income               | 2,574.29     | 3,196.94  | (0 -        | 27,000.02) |
| Pre-disease annual family income    | 30,891.67    | 38,363.12 | (0 -        | 32,000.01) |

Source: Study Database

Legend: SD - standard deviation / Min - minimum / Max - maximum / DOT - directly observed treatment.

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**Table 3.** Summary of the state of domestic poverty before and after Tuberculosis of participants from the 5 regions of Brazil in the period from June/2016 to July/2018 (n = 350).

| Variables               | Total    | Family income after TB |          | p-value |
|-------------------------|----------|------------------------|----------|---------|
|                         |          | Poor                   | Not poor |         |
| Family income before TB |          |                        |          |         |
| Poor                    | 101 (29) | 98 (71)                | 3 (1)    | < 0.001 |
| Not poor                | 249 (71) | 40 (29)                | 209 (99) |         |
| Total                   | 350      | 138 (39)               | 212 (61) |         |

Source: Study Database

Kappa = 0.7302 (p < 0.001) McNemar p < 0.001

Legend: TB - tuberculosis.

**Table 4.** Determinants of catastrophic costs related to Tuberculosis in Brazil of participants from the 5 Regions of Brazil in the period from June/2016 to July/2018 (n = 350).

| Level        | Group            | Determinant               | Category       | Multivariate model |      |      |         |      |      |      |         |
|--------------|------------------|---------------------------|----------------|--------------------|------|------|---------|------|------|------|---------|
|              |                  |                           |                | OR                 | LL   | UL   | p-value | aOR  | LL   | UL   | p-value |
| Distal       | sociodemographic | Education(years)          | 0-8            | 0.67               | 0.43 | 1.05 | 0.070   | 0.95 | 0.84 | 1.08 | 0.465   |
|              |                  |                           | > 8            | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  | Head of the family        | Patient        | 1.52               | 0.97 | 2.39 | 0.053   | 2.01 | 1.23 | 3.28 | 0.005   |
| Not patient  | 1.00             |                           |                |                    | 1.00 |      |         |      |      |      |         |
| Intermediate | Disease          | Treatment phase           | Intensive      | 1.44               | 0.87 | 2.38 | 0.121   | 1.51 | 0.89 | 2.55 | 0.120   |
|              |                  |                           | Maintenance    | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  | Type of TB                | Pulmonary      | 0.65               | 0.38 | 1.08 | 0.081   | 0.53 | 0.30 | 0.92 | 0.026   |
|              |                  |                           | Extrapulmonary | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  | Previous treatment for TB | Yes            | 1.65               | 0.90 | 3.00 | 0.077   | 1.77 | 0.95 | 3.29 | 0.068   |
|              |                  |                           | No             | 1.00               |      |      | 1.00    |      |      |      |         |
| Proximal     | Financial        | Income before TB          | Poor           | 2.99               | 1.80 | 4.87 | 0.000   | 2.65 | 1.22 | 5.76 | 0.014   |
|              |                  |                           | Not poor       | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  | Income after TB           | Poor           | 2.29               | 1.44 | 3.65 | 0.000   | 1.06 | 0.50 | 2.26 | 0.871   |
|              |                  |                           | Not poor       | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  | Formal work               | Yes            | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  |                           | No             | 2.20               | 1.37 | 3.55 | 0.000   | 1.48 | 1.13 | 1.94 | 0.004   |
|              |                  | Stopped working           | Yes            | 1.89               | 1.16 | 3.08 | 0.006   | 1.72 | 1.03 | 2.84 | 0.035   |
|              |                  |                           | No             | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  | Health plan               | Yes            | 1.00               |      |      | 1.00    |      |      |      |         |
|              |                  |                           | No             | 0.63               | 0.35 | 1.11 | 0.095   | 1.04 | 0.53 | 2.00 | 0.907   |

Source: Study Database

Legend: LL - lower limit / UL - upper limit / OR - odds ratio / aOR - adjusted odds ratio / TB - tuberculosis.

**Table 5.** Prevalence of catastrophic costs at different thresholds. The results are presented in general, and for participants living in poor versus not poor households, from the 5 regions of Brazil in the period from June/2016 to July/2018 (n = 350).

| Total catastrophic costs | 10%       | 15%       | 20%       | 25%       |
|--------------------------|-----------|-----------|-----------|-----------|
| Households               |           |           |           |           |
| General                  | 235 (67%) | 180 (51%) | 145 (41%) | 103 (29%) |
| Poor                     | 85 (84%)  | 71 (70%)  | 61 (60%)  | 44 (44%)  |
| Not poor                 | 150 (60%) | 109 (44%) | 84 (32%)  | 59 (24%)  |
| p-value                  | 0.000     | 0.000     | 0.000     | 0.000     |

Source: Study Database

diseases due to delay in treatment and should be better investigated. Non-poor households with formal employment may have access to sick pay<sup>30</sup> and, consequently, stop working and receive statutory sick leave during care. The poorest families may not have access to sick pay, because they may not have a formal contract, so they cannot stop working. Not stopping work is potentially bad as it can affect the patient's likelihood of successfully completing treatment.

Although the data show that the poor have had higher incidence of catastrophic cost (60%), the not poor also suffered catastrophic cost (32%), this can be explained by the fact that they could spend some money to speed up the diagnosis and have a situation more comfortable while seeking diagnosis and therapy, and conditions to cope with the need for additional food while recovering from the illness (if they have the money, they can spend it searching for better treatment conditions). These findings suggest that social protection schemes, such as food baskets and transport vouchers, are a social protection scheme that should be carried out for patients from poor families. In Brazil, several social protection measures are already in place<sup>2</sup>.

Free healthcare services are necessary but not sufficient in Brazil, the way the TB program is organized may need to be improved to advance prompt and effective care for TB patients. Furthermore, finding and treating the poorest people is the biggest challenge, as the focus on the vulnerable population requires different approaches that are not normally under the standard competence of health professionals in Brazil.

Financial assistance to patients who have lost income due to TB is not fully under the Ministry of Health's responsibility, and reducing costs for these TB-affected families in Brazil will require collaboration between the Ministry of Health and the Ministry of Social Development. The creation of a patient referral system for the Unified Social Assistance System carried out by the Unified Health System (UHS/SUS) will be the next step in the fight against TB in Brazil. This combination is a new approach that needs to be more innovative and focus on this vulnerable population with increasing financial difficulties due to TB, as an important path to TB elimination by 2035.

## CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

To our knowledge, this is the first survey in Brazil to estimate the proportion of catastrophic costs among people with all-drug-sensitive TB. The results provide a baseline for monitoring progress towards the WHO goal of ensuring that no TB-affected families face financial difficulty due to the disease and help to identify which families need support.

Households in Brazil are at risk of going through financial difficulties due to illness from TB, despite access to Primary Care available through the UHS/SUS. The catastrophic costs and the decrease in income for many families in Brazil observed during TB treatment can hinder access to health services and, consequently, the treatment of these patients.

Regarding the implications for practice, the findings of this investigation have the potential to direct specific intervention

strategies for low-income families that need a different look due to their financial situation. It is recommended that nurses act assertively in monitoring these families, seeking to maintain the treatment for as long as necessary to promote the cure.

The study also had some limitations. First, TB-related costs were self-reported, and participants may have experienced difficulty remembering costs incurred prior to diagnosis. Participants working in the informal, self-employed, and agricultural sectors may also have difficulty estimating incomes. Second, we are unable to assess costs for those patients who could not afford to seek treatment, such as the homeless who might underestimate our proportion of catastrophic costs. Finally, the cross-sectional design of the study means that we may have underestimated the use of coping strategies, as the risk of this activity will likely accumulate during treatment.

It is important to highlight the need to develop further research with participants who do not have access to the health system, as well as a study design to monitor these expenses on a monthly basis, since the cross-sectional design of the study may have underestimated the use of coping strategies and costs, as the risk tends to accumulate throughout the treatment.

## AUTHOR'S CONTRIBUTIONS

Study design. Leticia Molino Guidoni. Leticya dos Santos Almeida Negri. Geisa Fregona Carlesso. Eliana Zandonade. Ethel Leonor Noia Maciel.

Acquisition, analysis of data and interpretation of results. Leticia Molino Guidoni. Leticya dos Santos Almeida Negri. Geisa Fregona Carlesso. Eliana Zandonade. Ethel Leonor Noia Maciel.

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## REFERENCES

1. Sistema Único de Saúde (SUS): estrutura, princípios e como funciona (BR). Ministério da Saúde [internet]. Brasília (DF), 04 jan 2013 [cited 08 Jun 2020]. Available from: <https://www.saude.gov.br/sistema-unico-de-saude>
2. Sistema Único de Assistência Social (SUAS): o que é (BR). Ministério da Cidadania, Secretaria Especial do Desenvolvimento Social [site na internet], Brasília (DF), 07 jan 2020 [cited 08 Jun 2020]. Available from: <http://mds.gov.br/assuntos/assistencia-social/o-que-e>

3. Nhung NV, Hoa NB, Anh NT, Anh LTN, Siroka A, Lönnroth K et al. Measuring catastrophic costs due to tuberculosis in Vietnam. *Int J Tuberc Lung Dis*. 2018 set;22(9):983-90. <http://dx.doi.org/10.5588/ijtld.17.0859>. PMID:30092862.
4. Pedrazzoli D, Siroka A, Boccia D, Bonsu F, Nartey K, Houben R et al. How affordable is TB care? Findings from a nationwide TB patient cost survey in Ghana. *Trop Med Int Health*. 2018 ago;23(8):870-8. <http://dx.doi.org/10.1111/tmi.13085>. PMID:29851223.
5. Muttamba W, Tumwebaze R, Mugenyi L, Batte C, Sekibira R, Nkolo A et al. Households experiencing catastrophic costs due to tuberculosis in Uganda: magnitude and cost drivers. *BMC Public Health*. 2020;20(1):1409. <http://dx.doi.org/10.1186/s12889-020-09524-5>. PMID:32938411.
6. Fuady A, Houweling TAJ, Mansyur M, Burhan E, Richardus JH. Effect of financial support on reducing the incidence of catastrophic costs among tuberculosis-affected households in Indonesia: eight simulated scenarios. *Infect Dis Poverty*. 2019;8(1):10. <http://dx.doi.org/10.1186/s40249-019-0519-7>. PMID:30709415.
7. Tomeny EM, Mendoza VL, Marcelo DB, Barrameda AJD, Langley I, Abong JM et al. Patient-cost survey for tuberculosis in the context of patient-pathway modelling. *Int J Tuberc Lung Dis*. 2020 abr;24(4):420-7. <http://dx.doi.org/10.5588/ijtld.19.0206>. PMID:32317067.
8. Oxlade O, Murray M. Tuberculosis and poverty: why are the poor at greater risk in India? *PLoS One*. 2012;7(11):e47533. <http://dx.doi.org/10.1371/journal.pone.0047533>. PMID:23185241.
9. World Health Organization. WHO Report 2016. Global tuberculosis control. Geneva: WHO; 2017 [cited 08 Jun 2020]. Available from: <https://apps.who.int/iris/handle/10665/250441>
10. World Health Organization. WHO Report 2015. Global tuberculosis control. Geneva: WHO; 2015 [cited 08 Jun 2020]. Available from: [https://apps.who.int/iris/bitstream/handle/10665/191102/9789241565059\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/191102/9789241565059_eng.pdf?sequence=1)
11. World Health Organization. WHO Report 2019. Global tuberculosis control. Geneva: WHO; 2019 [cited 08 Jun 2020]. Available from: <https://apps.who.int/iris/bitstream/handle/10665/329368/9789241565714-eng.pdf>
12. Tanimura T, Jaramillo E, Weill D, Raviglione M, Lönnroth K. Financial burden for tuberculosis patients in low-and middle-income countries: a systematic review. *Eur Respir J*. 2014;43(6):1763-75. <http://dx.doi.org/10.1183/09031936.00193413>. PMID:24525439.
13. World Health Organization. Tuberculosis patient cost surveys: a handbook. Geneva: WHO; 2017 [cited 08 Jun 2020]. Available from: <https://apps.who.int/iris/bitstream/handle/10665/259701/9789241513524-eng.pdf?sequence=1>
14. Nhllema BM, Kemp J, Steenberg G, Theobald S, Tang S, Squire SB. Systematic analysis of TB and poverty. Geneva: WHO; 2003.
15. World Health Organization. The end TB strategy. Geneva: WHO; 2015 [cited 08 Jun 2020]. Available from: [https://www.who.int/tb/strategy/End\\_TB\\_Strategy.pdf?ua=1](https://www.who.int/tb/strategy/End_TB_Strategy.pdf?ua=1)
16. Fuady A, Houweling TAJ, Mansyur M, Richardus JH. Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of universal health coverage. *Infect Dis Poverty*. 2018 jan;7(1):3. <http://dx.doi.org/10.1186/s40249-017-0382-3>. PMID:29325589.
17. Steffen R, Menzies D, Oxlade O, Pinto M, de Castro AZ, Monteiro P et al. Patients' costs and cost-effectiveness of tuberculosis treatment in DOTS and non-DOTS facilities in Rio de Janeiro, Brazil. *PLoS One*. 2010;5(11):e14014. <http://dx.doi.org/10.1371/journal.pone.0014014>. PMID:21103344.
18. Costa JG, Santos AC, Rodrigues LC, Barreto ML, Roberts JA. Tuberculosis in Salvador, Brazil: costs to health system and families. *Rev Saude Publica*. 2005;39(1):122-8. <http://dx.doi.org/10.1590/S0034-89102005000100016>. PMID:15654469.
19. Prado TN, Wada N, Guidoni LM, Golub JE, Dietze R, Maciel EL. Cost-effectiveness of community health worker versus home-based guardians for directly observed treatment of tuberculosis in Vitória, Espírito Santo State, Brazil. *Cad Saude Publica*. 2011;27(5):944-52. <http://dx.doi.org/10.1590/S0102-311X2011000500012>. PMID:21655845.
20. Ministério da Saúde (BR). Manual de recomendações para o controle da tuberculose no Brasil. Brasília (DF): Ministério da Saúde; 2019 [cited 08 Jun 2020]. Available from: [https://bvsm.s.saude.gov.br/bvs/publicacoes/manual\\_recomendacoes\\_controle\\_tuberculose\\_brasil\\_2\\_ed.pdf](https://bvsm.s.saude.gov.br/bvs/publicacoes/manual_recomendacoes_controle_tuberculose_brasil_2_ed.pdf)
21. Harling G, Castro MC. A spatial analysis of social and economic determinants of tuberculosis in Brazil. *Health Place*. 2014;25:56-67. <http://dx.doi.org/10.1016/j.healthplace.2013.10.008>. PMID:24269879.
22. KNCV Tuberculosis Foundation. The tool to estimate patients' costs. Maanweg: KNCV; 2008 [cited 08 Jun 2020]. Available from: [http://www.stoptb.org/wg/dots\\_expansion/tbandpoverty/assets/documents/Tool%20to%20estimate%20Patients'%20Costs.pdf](http://www.stoptb.org/wg/dots_expansion/tbandpoverty/assets/documents/Tool%20to%20estimate%20Patients'%20Costs.pdf)
23. Nunes GF, Guidoni LM, Negri LSA et al. Adaptação transcultural do instrumento "Tool to estimate patient's costs" em municípios prioritários do Brasil no controle da tuberculose. *Esc Anna Nery*. 2018;22(4):e20180073.
24. Instituto Brasileiro de Geografia e Estatística. Síntese de indicadores sociais: uma análise das condições de vida da população brasileira. Rio de Janeiro: IBGE; 2017 [cited 08 Jun 2020]. Available from: <http://renastonline.ensp.fiocruz.br/sites/default/files/arquivos/recursos/liv101459.pdf>.
25. Wingfield T, Boccia D, Tovar M, Gavino A, Zevallos K, Montoya R et al. Defining catastrophic costs and comparing their importance for adverse tuberculosis outcome with multi-drug resistance: a prospective cohort study, Peru. *PLoS Med*. 2014 jul;11(7):e1001675. <http://dx.doi.org/10.1371/journal.pmed.1001675>. PMID:25025331.
26. Dados tuberculose no Brasil (BR). Sistema de Informação de Agravos de Notificação [internet], Brasília (DF), 2018 [cited 08 Jun 2020]. Available from: <http://portalsinan.saude.gov.br/tuberculose>
27. Wingfield T, Tovar MA, Huff D, Boccia D, Montoya R, Ramos E et al. The economic effects of supporting tuberculosis-affected households in Peru. *Eur Respir J*. 2016 nov;48(5):1396-410. <http://dx.doi.org/10.1183/13993003.00066-2016>. PMID:27660507.
28. Rudgard WE, Chagas NS, Gayoso R, Barreto ML, Boccia D, Smeeth L et al. Uptake of governmental social protection and financial hardship during drug-resistant tuberculosis treatment in Rio de Janeiro, Brazil. *Eur Respir J*. 2018 mar;51(3):1800274. <http://dx.doi.org/10.1183/13993003.00274-2018>. PMID:29567727.
29. Rudgard WE, Evans CA, Sweeney S, Wingfield T, Lönnroth K, Barreira D et al. Comparison of two cash transfer strategies to prevent catastrophic costs for poor tuberculosis-affected households in low- and middle-income countries: an economic modelling study. *PLoS Med*. 2017;14(11):e1002418. <http://dx.doi.org/10.1371/journal.pmed.1002418>. PMID:29112693.
30. E-gestor: Atenção Básica. Informação e gestão da Atenção Básica. Ministério da Saúde [internet], Brasília (DF), 2020 [cited 08 Jun 2020]. Available from: <https://egestorab.saude.gov.br/>