

# Follow-up of patients diagnosed with and treated for tuberculosis in Brazil: financial burden on the household

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# ABSTRACT

Objective: To evaluate the implications of the proportion of annual family income spent in the pre- and post-diagnosis periods in tuberculosis patients followed for after at least one year after completing tuberculosis treatment in Brazil. Methods: This was a crosssectional study of tuberculosis patients followed for at least one year after completing tuberculosis treatment in five Brazilian capitals (one in each region of the country). Results: A total of 62 patients were included in the analysis. The overall average cost of tuberculosis was 283.84 Brazilian reals (R\$) in the pre-diagnosis period and R\$4,161.86 in the post-diagnosis period. After the costs of tuberculosis disease, 71% of the patients became unemployed, with an overall increase in unemployment; in addition, the number of patients living in nonpoverty decreased by 5%, the number of patients living in poverty increased by 6%, and the number of patients living in extreme poverty increased by 5%. The largest proportion of annual household income to cover the total costs of tuberculosis was for the extremely poor (i.e., 40.37% vs. 11.43% for the less poor). Conclusions: Policies to mitigate catastrophic costs should include interventions planned by the health care system and social protection measures for tuberculosis patients with lower incomes in order to eliminate the global tuberculosis epidemic by 2035—a WHO goal in line with the United Nations Sustainable Development Goals.

Keywords: Tuberculosis/diagnosis; Tuberculosis/therapy; Costs and cost analysis; Financial stress; Brazil.

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## **INTRODUCTION**

Tuberculosis is an infectious disease that remains a major public health problem worldwide. It is one of the ten leading causes of death in the world<sup>(1)</sup> and can represent a significant financial burden because of the costs of diagnosis<sup>(2)</sup> and treatment (direct and indirect costs), exacerbating poverty.<sup>(3-5)</sup> In 2021, the WHO estimated that approximately 10.6 million new tuberculosis cases and 1.6 million tuberculosis deaths occurred worldwide.<sup>(1)</sup> The 2022 WHO Global Tuberculosis Report<sup>(1)</sup> showed that access to health services remains a challenge and that the global goals of prevention, diagnosis, and treatment agreed upon in the historic United Nations General Assembly session in September of 2018 will only be achieved through a multisectoral approach addressing the broader determinants of the tuberculosis epidemic and its socioeconomic impact. An estimated 5.4 billion U.S. dollars (US\$) were spent on tuberculosis diagnosis, treatment, and prevention in low- and middle-income countries in 2021. This was slightly less than the US\$5.5 billion spent in 2020 and down 10% less than the US\$6.0 billion spent in 2019. The US\$5.4 billion spent in 2021 represents less than 50% of the United Nation's global target of spending at least US\$13 billion annually by 2022.<sup>(1)</sup>

Brazil remains among the 30 countries with the highest burden of tuberculosis and tuberculosis/HIV coinfection,

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being considered a priority for disease control in the world by the WHO.<sup>(1)</sup> There were 68,271 new tuberculosis cases in Brazil in 2021, with an incidence rate of 32 cases per 100,000 population. In 2020, approximately 4,543 tuberculosis deaths were reported, with a mortality rate of 2.1 deaths per 100,000 population.<sup>(6)</sup> Geographic, social, cultural, and economic barriers to accessing tuberculosis treatment and poverty are major factors contributing to this situation and pose challenges to tuberculosis management.<sup>(1)</sup> In developing countries, such as Brazil, tuberculosis has increased poverty for underprivileged populations because of the costs of diagnosis and treatment, resulting in work absenteeism, unemployment, sequelae, and death.

The WHO has proposed a new strategy to eliminate tuberculosis worldwide through three high-level indicators. The strategy includes targets for major reductions in tuberculosis incidence, tuberculosis deaths, and costs faced by tuberculosis patients and their families between 2015 and 2035.<sup>(1,7)</sup>

Although the *Sistema Único de Saúde* (SUS, Brazilian Unified Health Care System) was built on the principles of universality, comprehensiveness, and equity,<sup>(8)</sup> it is the patient who bears the costs involved in the

diagnosis and management of tuberculosis. This can aggravate the economic burden on patients and their families and lead to impoverishment<sup>(9)</sup> as a result of direct costs and reduced income.

A conceptual framework of the financial burden of tuberculosis for the patient/household is shown in Figure 1. The household is the preferred unit of analysis in the evaluation of costs because all treatment-related decisions are made by the family on the basis of the household budget.<sup>(10)</sup> In response to the first perceived symptoms of the disease in the pre-diagnosis period (Figure 1), decisions are made regarding the search for the first health service for diagnosis. The health care system is an out-of-home resource that will be sought by the family and will provide access to the diagnosis of the disease and quality of care in the post-diagnosis period (Figure 1). Illness costs are classified into direct and indirect, and will depend on the type and severity of the illness and on the health service characteristics that influence access and quality of care (Figure 1). The costs of illness can lead to an impact on income, and, when they exceed the monthly household income, they can trigger coping strategies such as loans and asset sales (Figure 1). The cost burden corresponds to

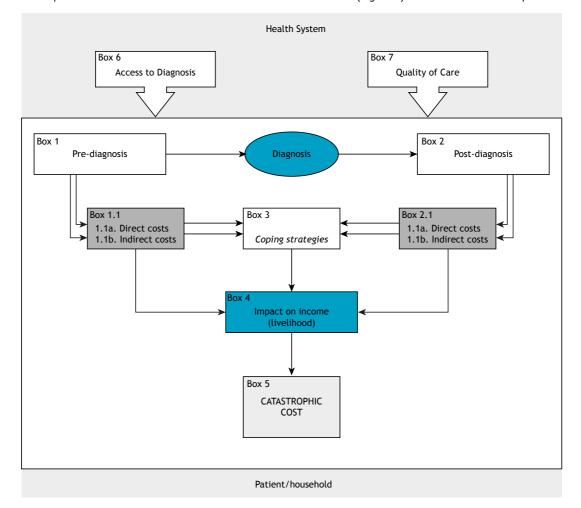


Figure 1. Conceptual framework for analysis of the economic burden of tuberculosis on the patient/household.

the sum of the direct and indirect costs expressed as a percentage of the annual household income; when higher than 20%, it can result in catastrophic costs (Figure 1),<sup>(7)</sup> which will likely force family members to cuts in consumption of basic necessities, the sale of assets, high levels of debt, and impoverishment.

In this context, the objective of the present study was to evaluate the implications of the proportion of annual family income spent in the pre- and post-diagnosis periods in tuberculosis patients followed for at least one year after completing tuberculosis treatment in Brazil.

### **METHODS**

In each of the five regions of Brazil, we selected a capital that is a priority city for tuberculosis control because of the high rates of new cases of tuberculosis: the city of Vitória, in the state of Espírito Santo, in southeastern Brazil; the city of Campo Grande, in the state of Mato Grosso do Sul, in central-western Brazil; the city of Recife, in the state of Pernambuco, in northeastern Brazil; the city of Porto Alegre, in the state of Rio Grande do Sul, in southern Brazil; and the city of Manaus, in the state of Amazonas, in northern Brazil. We selected a total of 14 health care facilities distributed among the five capitals and providing tuberculosis treatment in accordance with the Brazilian National Ministry of Health guidelines.

We performed a cross-sectional study of prospective data collected by interviewing tuberculosis patients enrolled in the *Programa Nacional de Controle da Tuberculose* (PNCT, Brazilian National Tuberculosis Control Program). The patients were interviewed at least one year after having completed the treatment of tuberculosis in one of the 14 health care facilities selected for inclusion in the study.

The study was approved by the Human Research Ethics Committee of the *Centro de Ciências da Saúde da Universidade Federal do Espírito Santo*, located in the city of Vitória, Brazil (Ruling no. 3.412.838, issued on June 25, 2019; Protocol no. 61080416.7.0000.5060).

The study population consisted of patients who had pulmonary or extrapulmonary tuberculosis and who were consecutively treated in any of the 14 selected health care facilities between June of 2016 and July of 2018. The sample size was calculated on the basis of a previous study,<sup>(11)</sup> being estimated at 362 participants. The inclusion criteria were as follows: being  $\geq$  18 years of age; and having completed tuberculosis treatment at least one year prior in any of the 14 selected health care facilities. Data were collected through face-to-face interviews performed between July of 2019 and July of 2021.

The Portuguese version of the WHO Tool to Estimate Patients' Costs, cross-culturally adapted to the needs of the SUS,<sup>(12)</sup> was used in order to estimate the costs of tuberculosis patients.

All costs were calculated for the period between the onset of reported symptoms and completion of 6-8

months of treatment. All costs related to the pre- and post-diagnosis periods were estimated in Brazilian reals (R\$), on the basis of the mean exchange rate for 2016 (i.e., US\$1.00 = R\$3.4901).<sup>(13)</sup> Direct medical costs included all of the expenses incurred by the patient as a result of tuberculosis disease, including tests, medications, follow-up, and hospitalization. Direct nonmedical costs included all of the expenses incurred by the tuberculosis patient for transportation to health care facilities, food purchased during the waiting time in the health care facility, and accommodation, as well as administrative expenses and special food costs. These costs were assessed for the patients and their caregivers. Indirect costs included absenteeism from work because of visits to health care facilities or hospitalization and loss of wages because of tuberculosisrelated work disability. To quantify the magnitude of the loss of income, the number of days absent from work was multiplied by the estimated daily income of the patient or caregiver. These costs were assessed for the patients and their caregivers. The total costs included all direct and indirect costs incurred in the pre- and post-diagnosis periods.

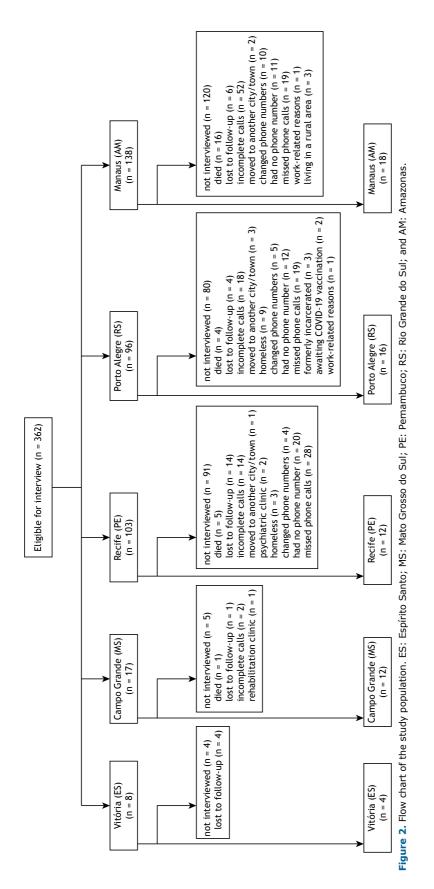
The WHO definition of catastrophic costs<sup>(9,14-16)</sup>—total costs (i.e., the sum of direct medical costs, direct nonmedical costs, and indirect costs) greater than 20% of the household's annual income (monthly family income multiplied by 12)—was used in order to estimate the proportion of the sample that experienced catastrophic costs associated with tuberculosis. The total catastrophic cost approach emphasizes the impact of lost revenue through overall indirect costs and also provides a clearer description of the severity of the financial impact.<sup>(17)</sup>

The statistical analysis was performed with the Stata statistical software package, version 14.0 (StataCorp LLC, College Station, TX, USA). The poverty level was classified in accordance with the World Bank guidelines, which establish extreme poverty for residents with a per capita income of less than 1/4 the minimum wage; poverty for residents with a per capita income of less than 1/2 the minimum wage; and nonpoverty for residents with a per capita income of more than 1/2 the minimum wage.<sup>(18)</sup>

## RESULTS

Of the 362 patients who were eligible for interview, only 62 (42 men and 20 women; 17.12%) were included in the analysis. Of those, 4 were followed in the city of Vitória, 12 were followed in the city of Campo Grande, 12 were followed in the city of Recife, 16 were followed in the city of Porto Alegre, and 18 were followed in the city of Manaus. Figure 2 shows a flow chart of the study population.

Of the 62 patients included in the analysis, 27 (43.5%) were in the 46- to 65-year age bracket (mean age,  $58.91 \pm 7.42$  years), 42 (68%) were male, 35 (56%) had had more than eight years of schooling, 44 (71%) were unemployed, 22 (35.5%) became unemployed







because of tuberculosis, 10 (16%) had an annual per capita income of less than R\$2,994.00, being extremely poor, and 33 (53%) had only one household member who earned an income. Overall, 15 patients (24%) had extrapulmonary tuberculosis, and 30 (48%) had comorbidities (Table 1).

With regard to costs incurred in the pre-diagnosis period, the overall average cost was R\$283.84, with direct medical costs accounting for R\$194.36 and direct nonmedical costs accounting for R\$89.48. Regarding the costs incurred in the post-diagnosis period, the overall average cost was R\$4,161.86 (per month of treatment), with direct medical costs accounting for R\$15.64, direct nonmedical costs accounting for R\$206.23, and indirect costs (loss of income) accounting for R\$3,940.09. The overall average cost for the caregiver (including direct and indirect costs) was R\$1,362.60 (Table 2).

Direct medical costs were higher in the pre-diagnosis period, and direct nonmedical costs were higher in the post-diagnosis period. During the pre-diagnosis period, none of the patients had indirect costs; however, the indirect costs incurred in the post-diagnosis period were higher than the direct costs incurred in both the preand post-diagnosis periods. During the pre-diagnosis period, almost 90% of the patients had direct costs; during the post-diagnosis period, 60% experienced indirect costs (loss of income; Table 2).

In the pre-diagnosis period, 22 patients (35%) incurred expenses pertaining to medications, 55 (89%) incurred travel expenses, and 25 (40%) incurred food expenses. In the post-diagnosis period, 11 patients (18%) incurred hospitalization costs, 55 (89%) incurred travel expenses, and 35 (56%) incurred special food costs. Indirect costs were incurred by 37 (60%) of the patients. Moreover, more than 30% had to borrow money for their treatment, and nearly 90% sought the SUS for a diagnosis: the PNCT, in 42%; a local public hospital, in 29%; and a primary health care clinic, in 18% (Table S1). A total of 40.32% of the patients included in the study experienced catastrophic costs related to tuberculosis (Table S2). Before the costs of tuberculosis disease, 42% of the study patients were unemployed; after the costs of tuberculosis disease, 71% became unemployed (Table S3).

Most (47) of the patients (76%) were nonpoor before the costs of tuberculosis disease and incurred higher mean total costs of tuberculosis (R\$4,361.30 for the less poor vs. R\$3,626.20 for the extremely poor); however, the largest proportion of annual household income to cover total costs was for the extremely poor (40.37% vs. 11.43%; Figure 3).

The willingness to pay to prevent tuberculosis was evaluated on the basis of the premise that patients had infinite resources. Most (74%) of the patients were willing to pay more than three times the Brazilian national minimum wage, whereas 14% were willing to pay up to one time the Brazilian national minimum wage. The main measure chosen by patients to alleviate the economic burden of tuberculosis was food, followed by a more efficient health care system (Figure 4).

# DISCUSSION

This study contributes to the global monitoring of the WHO End TB Strategy targets.<sup>(9,19)</sup> A total of 40.32% of the study participants experienced catastrophic costs associated with tuberculosis, despite the provision of diagnosis and treatment free of charge in the SUS.

In the present study, the costs incurred in the pre-diagnosis period were found to be lower than those incurred in the post-diagnosis period, a finding that is in disagreement with those of other studies, in which the pre-diagnosis period was reported as being critical.<sup>(20,21)</sup> This can be attributed to improved patient perception of tuberculosis symptoms. The fact that more than 40% of the study participants first sought medical attention under the PNCT prevented them from taking a complex path in seeking care and seeking out several doctors for the diagnosis of the disease. However, the high costs of medications in the pre-diagnosis period can be attributed to a delay in seeking medical attention in the SUS and a delay in the diagnosis of tuberculosis in the SUS.<sup>(22)</sup> Active case finding for early and increased detection of cases could minimize pre-diagnosis costs for patients.(23)

The increase in post-diagnosis costs can be attributed, at least in part, to an increased number of visits to health care facilities because of improved adherence to treatment and to an increased intake of special foods. In addition, the fact that patients are required to rest implies work absenteeism, which leads to loss of income and substantially contributes to increased treatment costs. In the present study, 89% of the patients had travel expenses and 56% had expenses for special foods during tuberculosis treatment. This finding suggests that it is essential to provide treatment as close as possible to where patients live. We found that 60% of the patients included in the present study experienced loss of income, and that family members also experienced work absenteeism because of the demands of patient care. Of the sample as a whole, 58% were employed before the diagnosis of tuberculosis, 43.5% were the only income earner in the family, 83% were male patients with pulmonary tuberculosis and 43.5% had relatives who stayed at home to take care of them. After the costs of tuberculosis disease, 71% of the patients included in the present study became unemployed, and 50% remained unemployed because of the physical and social consequences of tuberculosis (physical vulnerability and stigma); in addition, 53% of the households had only one income earner in the family. Risk factors for catastrophic costs include barriers to accessing the health care system, such as long travel times to reach health care facilities, and sociodemographic factors such as unemployment, older age, and fewer family members.<sup>(24)</sup> Studies have shown that tuberculosis remains associated with



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Unemployed because of tuberculosis	1 (100)	2 (67)	3 (75)	3 (75)	2 (25)	5 (41.7)	1	30) 30)	4 (33.3)	3(37.5)	(50)	7 (43.8)	1	2 (15.4)	3 (16.6)	9 (45)	131) (31)	22 (35,5)
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Component	Cost incurr	ed, patients <sup>a</sup>	
	Yes	No	Mean cost, R\$⁵
Pre-diagnosis			
Type of cost			
Direct cost			
Medical			
Tests	6 (10)	56 (90)	22.98
X-rays	7 (11)	55 (89)	13.76
Medications	22 (35)	40 (65)	157.62
Subtotal			194.36
Nonmedical			
Food	25 (40)	37 (60)	21.62
Travel	55 (89)	7 (11)	58.59
Accommodation	2 (3)	60 (97)	2.90
Administrative	3 (5)	59 (95)	6.37
Subtotal			89.48
TOTAL			283.84
Post-diagnosis			
Type of cost			
Direct cost			
Medical			
Follow-up	7 (11)	55 (89)	8.11
Hospitalization	11 (18)	51 (82)	7.43
Subtotal			15.54
Nonmedical			
Food	12 (19)	50 (81)	23.24
Travel	55 (89)	7 (11)	74.55
Accommodation	0	0	0.00
Administrative	0	0	0.00
Special foods	35 (56)	27 (44)	108.44
Subtotal			206.23
TOTAL			221.77
Indirect cost			
Loss of income	37 (60)	25 (40)	3,940.09
TOTAL		. ,	3,940.09
Caregiver (direct and indirect cost)	42 (68)	20 (32)	1,362.60

#### Table 2. Components of costs incurred by patients in the pre- and post-diagnosis periods.

R\$: Brazilian reals. <sup>a</sup>Values expressed in n (%). <sup>b</sup>In 2016, 1 U.S. dollar = 3.4901 Brazilian reals.

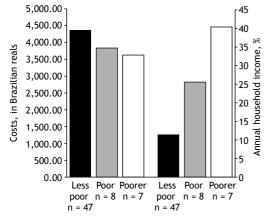
poverty worldwide<sup>(25,26)</sup> and pushes families deeper into poverty.(27,28)

Regarding the level of poverty, patients living in extreme poverty had a higher proportion of the annual household income spent on tuberculosis costs, incurring catastrophic costs. After the costs of tuberculosis disease, the number of patients living in nonpoverty decreased by 5%, the number of patients living in poverty increased by 6% and the number of patients living in extreme poverty increased by 5%. This shows that catastrophic costs continue to affect tuberculosis patients in Brazil, more predominantly the poor, thus contributing to increasing economic and social inequalities. In addition, these results highlight that access to tuberculosis diagnosis and treatment, available free of charge in the SUS, can be expensive for poor and extremely poor patients because high health costs imply a significant reduction in the resilience of families contending with high food and housing expenses.<sup>(3,29,30-36)</sup> This can result in increased stigmatization.<sup>(3,30,31)</sup>

In this context, it is important to highlight that the present study was carried out during the dismantling of social security and conditional cash transfer programs. This dismantling had a direct impact on tuberculosis-related social conditions, especially with regard to high indirect food costs. One study<sup>(37)</sup> showed that the Programa Bolsa Família alone had a direct effect on the outcomes of tuberculosis treatment and could greatly contribute to achieving the WHO End TB Strategy goals. Expanding the coverage of social protection programs can play an important role in alleviating extreme poverty and, indirectly, reducing the incidence of tuberculosis.(38)

More than 70% of the patients included in the present study were willing to pay more than three times the





**Figure 3.** Overview of the household poverty level and cost burden of tuberculosis on the patient/household.

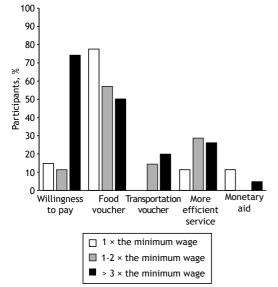


Figure 4. Willingness to pay to prevent tuberculosis and measures chosen to alleviate the burden of tuberculosis.

Brazilian national minimum wage to reduce the chance of an adverse health outcome. This is a useful indicator of how participants value life and health when social preferences are incorporated into public policies. The willingness-to-pay method is important because it seeks to assess indirect and intangible aspects of a disease or condition.<sup>(39)</sup> To reduce the economic burden of tuberculosis on the household,<sup>(11,40)</sup> social support measures must be implemented.

This is the first study in Brazil to assess the economic impact of tuberculosis on the household. The study has limitations. The number of participants included in the

analysis of the costs of tuberculosis disease was lower because of logistical barriers to data collection, mainly due to the COVID-19 pandemic, and because of the death or migration of patients who were eligible for follow-up. This may have introduced a selection bias and therefore affected the study results.

The study participants incurred economic losses in the pre-diagnosis period and severe loss of income in the post-diagnosis period. These losses resulted in unemployment and social sequelae. National and global policies to mitigate catastrophic costs should include interventions planned by health care systems to ensure early diagnosis of tuberculosis patients (through active case finding and contact investigation); social support to patients receiving tuberculosis treatment, so as to minimize the loss of income; and social protection measures for tuberculosis patients with lower incomes, so as to interrupt the relationship between tuberculosis and poverty, and, consequently, eliminate the global tuberculosis epidemic by 2035—a WHO goal in line with the United Nations Sustainable Development Goals.

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# **AUTHOR CONTRIBUTIONS**

RBL and ELNM conceptualized and designed the study. RBL, LMG, GF, and ELNM acquired, analyzed, and interpreted the data, and drafted the manuscript. SMVLO, DS, JSP, and DG critically reviewed the manuscript. RBL and ELNM had final responsibility to submit for publication. All authors agree to be accountable for all aspects of the work. All authors read and approved the final manuscript.

## **CONFLICTS OF INTEREST**

None declared.

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