Four of five tuberculosis patients experience catastrophic costs related to TB diagnosis and care in Timor-Leste

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_ S U M M A R Y

SETTING: Seventeen health care facilities that report to the national tuberculosis (TB) programme in Timor-Leste. Participants were TB patients.

OBJECTIVE: To determine the proportion of TB patients who experienced catastrophic costs due to their TB diagnosis and care, and the magnitude and composition of these costs.

DESIGN: This was a cross-sectional health facility-based survey, conducted in 17 DOTS centres between October 2016 and March 2017. TB patients were interviewed by trained nurses using a standardised questionnaire.

RESULTS: Among the 457 TB patients who participated (response rate 96.6%), the median age was 32 years; 39.2% were from the capital, Dili. The patient was the

main income earner in 26.3% of households. Annual individual and household incomes before and after TB diagnosis decreased by respectively 30.4% and 31.1%. Using a cut-off of 20% of annual household income, 83.0% of patients experienced catastrophic costs related to their TB diagnosis and care. Income loss and nutritional supplementation accounted for respectively 40.7% and 37.9% of these costs.

CONCLUSION: Four of five TB patients in Timor-Leste experienced catastrophic costs related to TB diagnosis and care. Financial and social protection to mitigate against these costs are urgently needed, in addition to universal health coverage.

KEY WORDS: Catastrophic costs; tuberculosis; economic burden; patient cost survey; Timor-Leste

THE WORLD HEALTH ORGANIZATION'S End Tuberculosis (TB) Strategy has the goal of ending TB as a public health problem by the year 2030. To measure the progress in reaching this ambitious goal, the Strategy has three main high-level indicators. Of these, estimated TB incidence and mortality have been reported by the WHO on an annual basis since 1997. The third of these indicators is the newly defined 'catastrophic costs' indicator, included in recognition of the financial barriers to TB care, which are substantial and likely to impede achievement of global TB elimination goals. Catastrophic costs 'refer to medical and non-medical out-of-pocket payments and indirect costs exceeding a given threshold (e.g., 20%) of the household's income'. The medical out-of-pocket income'.

Measurement of this indicator should enable governments to address demand-side cost barriers, which may be mitigated through a range of interventions including improving financial access to care, universal health coverage (UHC), extending patient-centred care delivery models that reduce time needed

for care-seeking and social protection interventions to mitigate loss of earnings due to care-seeking.

The financial costs to patients of a TB diagnosis and subsequent care are thought to be a significant impediment to further improving TB control.³ These can include medical costs (such as consultation fees), non-medical costs (such as transportation to the hospital) and indirect costs, such as time spent away from work or carer time. Previous studies have documented that TB patients often incur large costs related to their illness, including diagnosis and subsequent care.4,5 A recent systematic review that assessed the results of 49 studies on TB patient costs concluded that the total costs amounted to 58% (range 5-306) of annual individual income and 39% (range 4-148) of annual household income. 4 Such costs can create barriers to health-care access and treatment adherence, which can affect health outcomes6 and increase the risk of TB transmission. These costs can also be detrimental to the economic situation of households, especially for people who are already poor.4

Tuberculosis remains an issue of public health importance in the Asia-Pacific Region.⁷ The Democratic Republic of Timor-Leste (Timor-Leste), is a South-East Asian nation located at the eastern end of the Indonesian archipelago. Declared independent in 2002, the country has a long history of colonisation, occupation and civil war,⁸ and the national health system consequently was re-established in the early 2000s.⁸ Timor-Leste is classified as a lower middle-income economy,⁹ with a medium level of human development according to the Human Development Index;¹⁰ it has an estimated TB incidence rate of 498 cases per 100 000 population.²

We assessed the financial burden of TB in Timor-Leste to determine the proportion of patients who experienced catastrophic costs when accessing TB care. An additional objective of this study was to determine the main drivers of TB patient costs, including the magnitude and effects of these costs, to inform mitigation policies.

STUDY POPULATION AND METHODS

Study design and setting

Between October 2016 and March 2017, we conducted a cross-sectional health-facility based survey at 17 of 18 public health care facilities (DOTS) centres) that belong to the national TB programme (NTP) network in Timor-Leste (six DOTS centres in the capital Dili and 11 DOTS centres in 11 of 12 of the other municipalities of Timor-Leste). Data were not collected from the Oecusse DOTS centre due to logistical constraints in data collection from this site. TB diagnosis and care is not provided in the private sector in Timor-Leste, therefore there were no private sector clinics involved in this study.

Study population

The study population was all diagnosed TB patients (of all ages and with all types of TB) who had received TB treatment for ≥ 2 weeks in either the intensive phase or the continuation phase, who were being treated at participating DOTS centres in Timor-Leste. Newly diagnosed TB patients were enrolled at a follow-up visit after 2 weeks of TB treatment. Patients were interviewed in the intensive phase (i.e. the first 2 months of TB treatment for patients with fully susceptible disease or the first 6 months of TB treatment for patients with multidrug-resistant (MDR) TB¹¹ or the continuation phase (i.e., the TB treatment remaining after the intensive phase).

Sampling

We sampled from 17 of 18 DOTS centres affiliated with the NTP in Timor-Leste. The sample size, calculated using a WHO web calculator (http://samplesize.herokuapp.com), was 445 TB patients. This figure was calculated based on the number of

enrolled DOTS centres (n = 17) and the number of patients diagnosed and treated per year (n = 3800; unpublished data, Timor-Leste Ministry of Health). It assumed a level of 30% catastrophic costs, with 4% precision, a design effect of 1 and allowance for 5% refusal. We had a quota of 25 patients for 16 DOTS centres and a quota of 50 patients from one DOTS centre in Dili (as this centre had a higher TB caseload than all the other clinics).

Data collection

We used the standardised WHO questionnaire for TB patient cost surveys, with modifications for the Timor-Leste context. The questionnaire includes questions on the demographic and clinical characteristics of patients, income, direct medical costs, direct non-medical costs and indirect costs, coping mechanisms (i.e., taking out a loan, selling assets) and social consequences of TB (i.e., unemployment, divorce, taking a child out of school). Medical costs were defined as 'out of pocket payments for TB diagnosis and treatment made by TB patients'. Non-medical costs were defined as out of pocket 'payments related to the use of TB health services, such as payments for transportation, accommodation or food'. Indirect costs referred to 'patient or guardian lost time, lost wages (net of welfare payments) and lost income due to TB health care seeking and hospitalisation during TB care'. Income was determined by asking participants about their self-reported income in \$US (the currency used in Timor-Leste); if this was missing, an income estimate was made using self-reported household assets.

The interviewers were 16 district TB nurses who received a 3-day training course in October 2016, in Tetum, one of the official languages in Timor-Leste, from an experienced researcher. The interview tool was piloted during the training. Interviewers entered responses directly into a tablet as they interviewed 1–2 patients per day in a face-to-face interview in a private location at the DOTS centre. The patients were randomly selected for participation.

Analysis

We undertook a descriptive analysis reporting the numbers, proportions, means and standard deviations (SD) of the patients' demographic and clinical characteristics and income and costs. We calculated the mean out-of-pocket medical, non-medical and indirect costs for the period before TB treatment started (i.e. from the time of symptom onset) and during TB treatment (i.e. to treatment completion). We adopted the WHO definition of catastrophic costs and determined the proportion of TB patients whose total medical and non-medical out-of-pocket payments and indirect costs exceeded 20% of their annual household income.¹

As the patients reported only the costs of TB

treatment incurred during the phase of TB treatment they were undergoing at the time of the interview, we extrapolated the costs of the other treatment phase for each individual patient based on the median costs of that treatment phase incurred by the other patients in the survey. We determined the proportion of TB patients who incurred catastrophic costs and the amount of dissaving incurred. The indirect costs were calculated using two methods recommended by the WHO.12 The output approach used self-reported income to estimate income change before TB and during TB care. 12 The human capital approach valued the time spent seeking and receiving care during the TB episode by multiplying this time (in hours) by an individual hourly income, with this hourly income based on individual income data reported by the survey participants.12 We also used a 'dissavings' approach whereby we calculated the proportion of TB patients who experienced any dissavings (i.e. sold assets, borrowed money, etc.). All analyses were carried out using Stata v15.0 (StataCorp, College Station, TX USA).

Ethical considerations

Ethical approval was provided by the Australian National University Human Research Ethics Committee (Canberra, ACT, Australia) (2016/110) and the Timor-Leste Ministry of Health Ethics Committee (Dili, Timor-Leste) (HRD-2016-0006). Written informed consent was obtained from all participants. For TB patients aged <15 years of age, informed consent was obtained from a parent or guardian.

RESULTS

Of 473 TB patients approached to participate in the study, 457 (96.6%) were eligible to participate and were included for analysis (Table 1). Fourteen of the 473 were excluded during data cleaning as they had received <2 weeks of TB treatment and two were excluded as they did not provide written informed consent.

Of the 457 TB patients who were eligible, 50.6% were male, the median age was 32 years and 5.9% were children (aged <15 years) (Table 1). The majority of TB patients were receiving TB treatment for the first time (n = 415, 90.8%) and 275 (60.2%) were in the continuation phase (Table 1). One patient was positive for the human immunodeficiency virus (HIV); none of the patients had drug-resistant TB (Table 1). Thirty-nine per cent of patients were from the capital, Dili (n = 179) and 206 (44.6%) were employed prior to their TB diagnosis (Table 1).

The costs incurred were mainly related to indirect costs, with income loss responsible for 38.8% of all costs, followed by food-related costs after diagnosis (37.8%), travel after diagnosis (14.2%) and medical costs after diagnosis (8.2%) (Table 2). Only 0.5% of

Table 1 Sociodemographic, clinical and economic characteristics of TB patients who participated in the national TB patient cost survey, Timor Leste, 2016-2017 (n = 457)

Characteristics	n (%)
Sociodemographic characteristics	
Sex Male	231 (50.6)
Female	226 (49.4)
Age, years, median [IQR]	32 [22–52]
Children < 15 years	27 (5.9)
Municipality of health facility	
Aileu	25 (5.5)
Ainaro	25 (5.5)
Baucau Bobonaru	25 (5.5) 26 (5.7)
Covalima	27 (5.9)
Dili	179 (39.2)
Ermera	22 (4.8)
Lautem	27 (5.9)
Liquica	26 (5.7)
Manatuto	24 (5.3)
Manufahi	25 (5.5)
Viqueque Education status	26 (5.7)
Not yet started school	14 (3.1)
Did not attend school	135 (29.5)
Should be in school but not attending	4 (0.9)
Pre-school	1 (0.2)
Primary school	98 (21.4)
Secondary school	134 (29.3)
University	69 (15.1)
Vocational Unknown	1 (0.2) 1 (0.2)
Employment status pre-TB	1 (0.2)
Employed or has a job	204 (44.6)
House duties	33 (7.2)
Student	63 (13.8)
Retired	0
Long-term disabled	1 (0.2)
Unemployed Unknown	154 (33.7) 2 (0.4)
	2 (0.4)
Clinical characteristics	
Type of TB Pulmonary, bacteriologically confirmed	267 (58.4)
Pulmonary, clinically diagnosed	142 (31.1)
Extrapulmonary, bacteriologically confirmed	9 (2.0)
Extrapulmonary, clinically diagnosed	39 (8.5)
Drug resistance status	
Drug-susceptible	457 (100)
Drug-resistant	0
Phase of TB treatment	102 /20 0\
Intensive Continuation	182 (39.8) 275 (60.2)
HIV status	273 (00.2)
Positive	1 (0.2)
Negative	404 (88.4)
Unknown	52 (11.4)
Retreatment status	
New	415 (90.8)
Retreatment or relapse	36 (7.9)
Unknown Treatment initiation delay	6 (1.3)
Treatment delay >4 weeks	22 (4.8)
Treatment delay, weeks, mean \pm SD ($n = 160$)	0.14 ± 0.35
Total	457
.5.01	137

TB = tuberculosis; IQR = interquartile range; HIV = human immunodeficiency virus; SD = standard deviation.

all costs were incurred before diagnosis, for medical costs (0.3%) and non-medical costs (0.2%) (Table 3). The overall mean cost of a TB diagnosis and care was US\$2594.35 (Table 2). The patient was the main

Table 2	Estimated mean patient costs for tuberculosis care in \$US by cost category, Timor Leste,
2016-20	7 (n = 457)

Type of costs	Costs, \$US mean (95%CI)	Proportion of costs* (%)
Pre-diagnosis Medical Non-medical	5.18 (2.82–7.55) 6.73 (4.49–8.97)	(0.2) (0.3)
Post diagnosis Medical Non-medical Travel Accommodation Food	211.68 (21.80–401.55) 1364.84 (1211.80–1517.87) 369.43 (300.44–438.43) 14.41 (8.36–20.47) 980.99 (866.49–1095.49)	(8.2) — (14.2) (0.5) (37.8)
Total medical (pre- and post-diagnosis) Total non-medical (pre- and post-diagnosis) Total income loss (post-diagnosis, $n=453$) Total overall* (pre- and post-diagnosis)	216.86 (26.97–406.75) 1371.57 (1218.44–1524.69) 1005.92 (780.61–1231.23) 2585.54 (2229.04–2942.04)	(8.4) (52.8) (38.8) (100)

^{*} Includes medical costs, non-medical costs and income loss (at the household level). \$US = United States dollars; CI = confidence interval.

income earner in 26.3% (n = 106) of households (Table 3). When comparing the annual individual and annual household incomes before and after TB diagnosis, they decreased by respectively 30.4% and 31.1% (Table 3). The proportion of patients with catastrophic costs was 83.0% using the output approach and 85.0% using the human capital approach (Table 4).

In addition, 26.4% (n = 120) of patients reported any dissaving; of these 73 (60.8%) sold assets, 50 (41.7%) took out a loan and 23 (19.2%) used their savings to finance their TB care (Table 5). The main social consequences of TB were food insecurity (n = 70, 15.4%), loss of a job or unemployment (n = 66, 14.5%) and withdrawal of a child from school (n = 16, 3.5%) (Table 5). There were 196 patients (44.0%) who lost some days of work and only 1.1% (n = 5) received any kind of social support (Table 5).

The distribution of costs was different for people in different wealth quintiles, with the poorest incurring a greater proportion of medical costs before diagnosis, costs related to food and income loss compared to the other wealth quintiles (Figure).

DISCUSSION

We found that four of five TB patients in Timor-Leste experienced 'catastrophic costs' associated with TB care, meaning that the patient paid the equivalent of ≥20% of their annual household income for their TB diagnosis and care. Household annual income and individual household income decreased respectively by 30% and 31%, when comparing pre- and post-TB income. Those in poorer income groups were more likely to dissave or employ coping mechanisms. The end result of this is that TB is a financially crippling and potentially impoverishing condition in Timor-Leste.

The proportion of TB patients who experienced catastrophic costs was higher in our survey compared to the results from other surveys that used the same methodology, where respectively 63%, 64% and 60% of TB patients experienced catastrophic costs in Vietnam, ¹³ Ghana ¹⁴ and Myanmar. ¹⁵ Using a slightly different methodology, this figure was much lower in neighbouring Indonesia, at 36% (although it was 83% for patients with MDR-TB). ¹⁶

Other studies have found that seeking TB care can be financially catastrophic and that these costs affect

Table 3 Annual individual and household income pre- and post-TB and percentage of decrease in income among TB patients, Timor Leste, 2016–2017 (n = 457)

Annual income	Amount \$US mean (SD)	(95%CI)
Household income Reported annual household income pre-TB ($n=454$) Reported annual household income post-TB ($n=455$) Difference in annual household income pre- and post-TB, % decrease Patient was the main income earner in household, n (%)	3012.01 (4092.00) 2076.55 (3655.78) 953.46 (-31.1) 120 (26.3)	(2634.62–3389.45) (1739.75–2413.36) —
Individual income Reported annual individual income pre-TB ($n=456$) Reported annual individual income post-TB ($n=448$) Difference in annual individual income pre and post-TB, % decrease	1297.25 (2349.12) 902.60 (2044.24) 394.65 (-30.4)	(1081.06–1513.43) (712.79–1092.4)

TB = tuberculosis; \$US = United States dollars; SD = standard deviation; CI = confidence interval.

Table 4 Number and proportion of tuberculosis patients facing catastrophic costs by cost calculation method, Timor-Leste, 2016–2017

Cost calculation method	Patients with catastrophic costs <i>n</i>	Proportion of patients with catastrophic costs % (95%CI)		
Output approach ($n = 452$)	375	83.0 (79.5–86.4)		
Human capital approach ($n = 452$)	384	85.0 (81.3-88.1)		
Any dissavings approach ($n = 457$)	121	26.5 (22.5–30.8)		

CI = confidence interval

different groups of patients unequally. In a study involving TB patients and controls from 'shantytowns' in Peru, 39% of TB patients incurred catastrophic costs.⁶ Poorer patients spent less money on treatment but this amounted to a greater proportion of their overall income (27% vs. 48% respectively for the least poor and the poorest households).6 In another study from Malawi, the authors found that TB patients incurred US\$13 (or 18 days of income) for TB care, and lost 22 days of working time due to their illness.¹⁷ Poor patients incurred greater absolute costs (248% vs. 129% of monthly income) than less poor patients.¹⁷ Another multi-country study that assessed TB treatment costs in Ghana, Vietnam and the Dominican Republic, found that up to 37% of TB patients had to sell property and up to 47% borrowed money to fund their TB care. 18 Other studies report similar results; one of further impoverishment due to TB. 19-21

Our results also showed that the greatest proportion of costs for TB patients in Timor-Leste were attributed to lost income or money spent on food and nutritional supplements, totalling almost 80% of all

costs. The comparatively high proportion of costs attributed to food and nutritional supplementation is puzzling, however, food insecurity was also reported by 15% of patients overall. In two other patient cost studies, conducted using the same methodology, the proportion of costs attributed to food was also relatively high. 13,14 In Viet Nam, the mean total costs borne by TB-affected households for food and nutritional supplements was respectively US\$296 and US\$131, and 22% of households reported food insecurity.¹³ In another survey conducted in Ghana, between 21% to 36% of total costs were attributed to expenditure on food, after diagnosis. 14 There may be a need to better understand why patients are spending relatively large amounts of money on food and nutritional supplements in Timor-Leste. One reason may be that health-care workers recommend to TB patients that they increase their protein intake after a diagnosis of TB, however, this is an anecdotal finding. Furthermore, patients had little access to social protection to potentially offset these losses; only five patients (1.1% of the overall sample) reported access to social protection. Direct medical costs were

Table 5 Number and proportion of TB patients who experienced dissaving strategies, social consequences, self-reported financial impact and who received social support during TB care, by wealth quintile, Timor-Leste, 2016–2017

	Income quintiles					
	Poorest (n = 91) n (%)	Less poor (n = 114) n (%)	Average (n = 78) n (%)	Less wealthy (n = 83) n (%)	Wealthiest (n = 88) n (%)	Total (n = 454) n (%)
Dissaving strategies						
Took out a loan, $n = 447$	11 (12.2)	20 (17.7)	8 (10.4)	9 (11.1)	2 (2.3)	50 (11.2)
Use of savings, $n = 450$	1 (1.1)	2 (1.8)	5 (6.4)	4 (4.9)	11 (12.6)	23 (5.1)
Sale of assets, $n = 441$	18 (20.5)	28 (25.0)	14 (18.2)	7 (8.6)	6 (7.2)	73 (16.6)
Any one of the three dissaving strategies, $n = 454$	23 (25.3)	37 (32.5)	24 (30.1)	19 (22.9)	17 (19.3)	120 (26.4)
Social consequences						
Food insecurity	11 (12.1)	37 (32.5)	8 (10.3)	11 (13.3)	3 (3.4)	70 (15.4)
Divorce or separated from spouse or partner	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Loss of job or employment	14 (15.4)	22 (19.3)	7 (9.0)	11 (13.3)	12 (13.6)	66 (14.5)
Child interrupted schooling	3 (3.3)	8 (7.0)	1 (1.3)	2 (2.4)	2 (2.3)	16 (3.5)
Social exclusion	1 (1.1)	0 (0.0)	1 (1.3)	0 (0.0)	0 (0.0)	2 (0.4)
Any days of work lost, $n = 445$	50 (55.6)	48 (43.2)	29 (37.7)	38 (48.1)	31 (35.2)	196 (44.0)
Self-reported financial impact						
No impact	3 (3.3)	2 (1.8)	0 (0.0)	1 (1.2)	9 (10.2)	15 (3.3)
Little impact	48 (52.8)	56 (49.1)	41 (52.6)	37 (44.6)	42 (47.7)	224 (49.3)
Moderate impact	25 (27.5)	38 (33.3)	29 (37.2)	38 (45.8)	29 (33.0)	159 (34.0)
Serious impact	8 (8.8)	18 (15.8)	7 (9.0)	5 (6.0)	8 (9.1)	46 (10.1)
Very serious impact	7 (7.7)	0 (0.0)	1 (1.3)	2 (2.4)	0 (0.0)	10 (2.2)
Household received social support after TB diagnosis, $n = 448$	1 (1.1)	0 (0.0)	2 (2.6)	1 (1.2)	1 (1.2)	5 (1.1)

TB = tuberculosis.

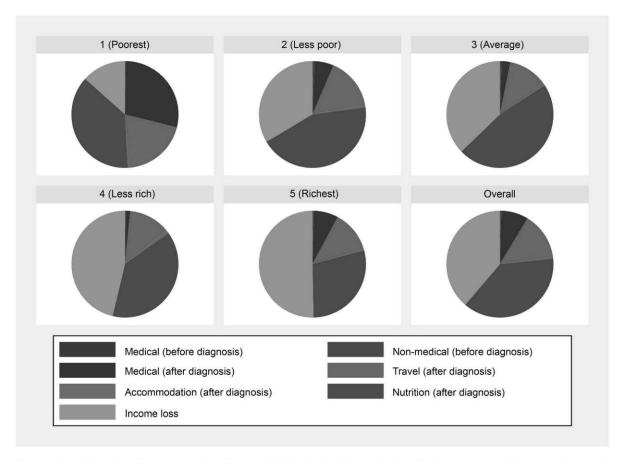


Figure Proportion of total costs incurred as direct and indirect costs, before and after TB diagnosis among TB patients, by wealth quintile and all patients taken together, with no wealth quintile, Timor–Leste, 2016–2017 (n = 457).

comparatively low, at 8.4% of overall costs, but those in the poorest wealth quintile spent a higher proportion of costs on medical care.

Strategies to mitigate costs such as lost income might include sickness benefits, unemployment benefits, or other forms of social welfare or psycho-social support.^{22,23} The small proportion of patients who had access to social protection indicates that access to social welfare is very limited, possibly reflecting the fragility of the social support sector in Timor-Leste.

One of the strengths of our study was that we conducted the survey nationwide with 17 of 18 DOTS centres represented, including urban and rural sites, with a high level of participation. This study also has several limitations, however. First, it included only patients who accessed health-care facilities linked to the NTP, meaning that private facilities not linked to the NTP were not included. However, one private health care clinic in Dili was included. Second, this was a cross-sectional survey with forward extrapolations on patient costs. While this is a practical method given the context and is recommended by the WHO, the costs may not reflect the true costs of illness. Longitudinal methods of determining patient costs may provide more accurate

measures, although are more complex to implement. Third, recall bias is a concern when evoking costs incurred in the past. As much as possible we used prompts to assist patients in recalling costs but it is possible that patients' recollection of costs may have been inaccurate. Fourth, we did not interview patients who were lost to follow-up—these patients may have abandoned care due to high costs13,24 and therefore we may have underestimated the proportion of patients with catastrophic costs. Fifth, we used self-reported income as the measure of income in this survey. Other methods of reporting or estimating income, such as household consumption or expenditure, may be more accurate in settings such as Timor-Leste where the majority of the population is employed in the informal employment sector. Future methodological work on measuring income may determine which approach is most precise.²⁵

CONCLUSIONS

The cost of TB care is catastrophic for patients in Timor-Leste. The majority of TB patients spent 20% or more of their annual household income on their TB diagnosis and care. Income loss and nutritional

supplementation account for a large proportion of these costs. The Timor-Leste NTP should further investigate how to mitigate the financial costs of TB care for TB patients and their households so that the economic burden of TB can be reduced.

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References

- 1 World Health Organization. Implementing the End TB Strategy: the essentials. Geneva, Switzerland: WHO, 2015.
- 2 World Health Organization. Global tuberculosis report, 2018. WHO, 2018. WHO/CDS/TB/2018.20. Geneva, Switzerland: WHO, 2018.
- 3 Lönnroth K, Glaziou P, Weil D, Floyd K, Uplekar M, Raviglione M. Beyond UHC: monitoring health and social protection coverage in the context of tuberculosis care and prevention. PLoS Med 2014; 11(9): e1001693.
- 4 Tanimura T, Jaramillo E, Weil 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): 1763–1775
- 5 Barter D, Agboola S, Murray M, Barnighausen T. Tuberculosis and poverty: the contribution of patient costs in sub-Saharan Africa—a systematic review. BMC Public Health 2012; 12(980): 1–34.
- 6 Wingfield T, Boccia D, Tovar M, 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; 11(7): e1001675.
- 7 World Health Organization Western Pacific Region Office. Regional framework for action on implementation of the End TB Strategy in the Western Pacific: 2016–2020. Manila, Philippines: WHO Western Pacific Region Office, 2016.
- 8 Alonso A, Brugha R. Rehabilitating the health system after conflict in East Timor: a shift from NGO to government leadership. Health Policy Plan 2006; 21(3): 206–216.
- 9 World Bank. World Bank country and lending groups. Washington, DC, USA: World Bank Group, 2017. https://

- datahelpdesk.worldbank.org/knowledgebase/articles/906519world-bank-country-and-lending-groups Accessed August 2019
- 10 United Nations Development Programme. Global 2016 Human Development Report. New York, NY, USA: UN, 2016.
- 11 World Health Organization. Treatment of tuberculosis: guidelines. 4th ed. Geneva, Switzerland: WHO, 2010.
- 12 World Health Organization. Tuberculosis patient cost surveys: a handbook. Geneva, Switzerland: WHO, 2017.
- 13 Nhung N, Hoa N, Anh N, et al. Measuring catastrophic costs due to tuberculosis in Vietnam. Int J Tuberc Lung Dis 2018; 22(9): 983–990.
- 14 Pedrazzoli D, Siroka A, Boccia D, et al. How affordable is TB care? Findings from a nationwide TB patient cost survey in Ghana. Trop Med Int Health 2018; 23(8): 870–878.
- 15 World Health Organization. Global tuberculosis report, 2017. WHO/HTM/TB/2017.23. Geneva, Switzerland: WHO, 2017.
- 16 Fuady A, Houweling T A, Mansyur M, Richardus J H. Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of universal health coverage. Infect Dis Poverty 2018; 7(1): 3.
- 17 Kemp J R, Mann G, Simwaka B N, Salaniponi F M, Squire S B. Can Malawi's poor afford free tuberculosis services? Patient and household costs associated with a tuberculosis diagnosis in Lilongwe. Bull World Health Organ 2007; 85(8): 580–585.
- 18 Mauch V, Bonsu F, Gyapong M, et al. Free tuberculosis diagnosis and treatment are not enough: patient cost evidence from three continents. Int J Tuberc Lung Dis 2013; 17(3): 381– 387.
- 19 Foster N, Vassall A, Cleary S, Cunnama L, Churchyard G, Sinanovic E. The economic burden of TB diagnosis and treatment in South Africa. Soc Sci Med 2015; 130: 42–50.
- 20 Laurence Y V, Griffiths U K, Vassall A. Costs to health services and the patient of treating tuberculosis: a systematic literature review. Pharmacoeconomics 2015; 33(9): 939–955.
- 21 Muniyandi M, Ramachandran R, Gopi P, et al. The prevalence of tuberculosis in different economic strata: a community survey from South India. Int J Tuberc Lung Dis 2007; 11(9): 1042–1045.
- 22 Boccia D, Pedrazzoli D, Wingfield T, et al. Towards cash transfer interventions for tuberculosis prevention, care and control: key operational challenges and research priorities. BMC Infect Dis 2016; 16(1): 307.
- 23 van Hoorn R, Jaramillo E, Collins D, Gebhard A, van den Hof S. The effects of psycho-emotional and socio-economic support for tuberculosis patients on treatment adherence and treatment outcomes—a systematic review and meta-analysis. PLoS One 2016; 11(4): e0154095.
- 24 Munro S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. PLoS Med 2007; 4(7): 1230– 1245.
- 25 Sweeney S, Mukora R, Candfield S, Guinness L, Grant A D, Vassall A. Measuring income for catastrophic cost estimates: limitations and policy implications of current approaches. Soci Sci Med 2018; 215: 7–15.

RESUME

CONTEXTE: Dix-sept structures de soins de santé qui envoient des rapports au Programme national tuberculose (TB) de Timor Leste. Les participants ont été des patients TB.

OBJECTIF: Déterminer la proportion de patients TB ayant subi des coûts catastrophiques dus à leur diagnostic et soins de TB et la magnitude et la composition de ces coûts.

SCHÉMA: Enquête transversale basée en structures de santé, réalisée dans 17 centres DOTS entre octobre 2016 et mars 2017. Les patients TB ont été interviewés par des infirmiers formés, grâce à un questionnaire standardisé. RÉSULTATS: Un total de 457 patients TB ont participé (taux de réponse 96,6%). L'âge médian des répondants a été de 32 ans; 39,2% venaient de la capitale, Dili. Le

patient était la principale source de revenus dans 26,3% des foyers. Les revenus annuels individuels et familiaux avant et après le diagnostic de TB ont diminué de 30,4% et de 31,1%, respectivement. Avec un seuil de 20% de revenu annuel du foyer, 83,0% des patients ont subi des coûts catastrophiques liés à leur diagnostic et traitement de TB. La perte de revenu et la supplémentation nutritionnelle ont représenté 40,7% et 37,9% de ces coûts, respectivement.

CONCLUSION: Quatre patients TB sur cinq subissent des coûts catastrophiques liés au diagnostic et au traitement de TB à Timor Leste. Il est urgent de mettre en œuvre, en plus de la couverture de santé universelle, des mesures de protection financière et sociale afin d'atténuer ces coûts.

RESUMEN

MARCO DE REFERENCIA: Diecisiete establecimientos de salud que presentan informes al Programa Nacional contra la Tuberculosis (TB) de Timor-Leste. En el estudio participaron pacientes con diagnóstico de TB.

OBJETIVO: Determinar la proporción de pacientes con TB que hacen frente a costos catastróficos debidos al diagnóstico y la atención de la TB y evaluar la magnitud y el origen de estos costos.

MÉTODO: Se realizó un estudio transversal en 17 centros de atención de salud que practican el tratamiento DOTS, de octubre del 2016 a marzo del 2017. Mediante un cuestionario normalizado, el personal de enfermería capacitado entrevistó a los pacientes con tuberculosis.

RESULTADOS: Participaron en el estudio 457 pacientes con diagnóstico de TB (tasa de respuesta 96,6%). La mediana de edad de quienes respondieron fue 32 años; el

39,2% residía en la capital, Dili. El paciente era la principal fuente de ingresos de la familia en el 26,3% de los hogares. Se observó una disminución de los ingresos anuales individuales (-30,4%) y familiares (-31,1%) antes y después del diagnóstico de TB. Al aplicar un umbral de 20% del ingreso familiar anual, el 83,0% de los pacientes hicieron frente a costos catastróficos debidos al diagnóstico de la TB y su tratamiento. La pérdida del ingreso representó el 40,7% de estos costos y los complementos nutricionales el 37,9%.

CONCLUSIÓN: Cuatro de cada cinco pacientes con TB hacen frente a costos catastróficos relacionados con el diagnóstico y el tratamiento de la enfermedad en Timor-Leste. Es urgente instaurar medios de protección económica y social con el fin de mitigar estos costos, además de ofrecer acceso a la atención de salud para todos.