

How affordable is TB care? Findings from a nationwide TB patient cost survey in Ghana

Debora Pedrazzoli¹, Andrew Siroka², Delia Boccia¹, Frank Bonsu³, Kenneth Nartey⁴, Rein Houben¹ and Josephine Borghi⁵

¹ Department of Infectious Disease Epidemiology, London School of Hygiene and Tropical Medicine, London, UK

² World Health Organization, Global Tuberculosis Programme, Geneva, Switzerland

³ National Tuberculosis Control Programme, Ghana Health Service, Accra, Ghana

⁴ Dodowa Health Research Centre, Dodowa, Ghana

⁵ Department of Global Health and Development, London School of Hygiene and Tropical Medicine, London, UK

Abstract

OBJECTIVES Tuberculosis (TB) is known as a disease of the poor. Despite TB diagnosis and care usually being offered for free, TB patients can still face substantial costs, especially in the context of multi-drug resistance (MDR). The End TB Strategy calls for zero TB-affected families incurring ‘catastrophic’ costs due to TB by 2025. This paper examines, by MDR status, the level and composition of costs incurred by TB-affected households during care seeking and treatment; assesses the affordability of TB care using catastrophic and impoverishment measures; and describes coping strategies used by TB-affected households to pay for TB care.

METHODS A nationally representative survey of TB patients at public health facilities across Ghana.

RESULTS We enrolled 691 patients (66 MDR). The median expenditure for non-MDR TB was US \$429.6 during treatment, *vs.* US\$659.0 for MDR patients (P -value = 0.001). Catastrophic costs affected 64.1% of patients. MDR patients were pushed significantly further over the threshold for catastrophic payments than DS patients. Payments for TB care led to a significant increase in the proportion of households in the study sample that live below the poverty line at the time of survey compared to pre-TB diagnosis. Over half of patients undertook coping strategies.

CONCLUSION TB patients in Ghana incur substantial costs, despite free diagnosis and treatment. High rates of catastrophic costs and coping strategies in both non-MDR and MDR patients show that new policies are urgently needed to ensure TB care is actually affordable for TB patients.

keywords TB, affordability, catastrophic costs, impoverishment, coping strategies, Ghana

Introduction

Much has been achieved in tuberculosis (TB) control since the World Health Organization (WHO) declared it a global emergency in the mid-nineties [1]. Yet TB, with an estimated 10.4 million new cases and 1.7 million TB-related deaths globally in 2016, is now the leading cause of mortality from a single infection [2].

TB also represents an equity challenge. While TB is not solely a disease of the poor, poverty and inequity fuel the TB epidemic [3, 4]. Poverty increases the risk of acquiring TB infection and developing the disease through more proximal risk factors such as malnutrition and overcrowded living conditions [5–7]. Poverty also limits access to care for TB patients, particularly in low- and middle-income countries (LMICs), where health care financing is characterised by a heavy reliance on out-of-

pocket (OOP) payments and the limited coverage of pre-payment mechanisms (e.g. taxation, health insurance) [8]. Even when TB diagnosis and treatment are provided free of charge, TB patients often incur transport, accommodation and time costs associated with care seeking [9]. Costs can be a deterrent to accessing diagnosis and care in the first place for those with constrained incomes [10], and where patients do seek care, costs reduce available income making the patient and their household more vulnerable to financial hardship [11]. Where households struggle to afford care, TB patients will be less likely to adhere to treatment and may fail to complete it [12], thus leading to increased TB transmission in the household and community, as well as exacerbating individual morbidity and mortality [13]. Affordability is a particular concern for treatment of multi-drug resistant (MDR)-TB which often lasts for more than 18 months [14, 15].

Recognising this challenge, the WHO's End TB Strategy for the 2015–2035 era includes a target of preventing any TB patient from incurring 'catastrophic' costs due to TB, or ensuring that costs do not exceed 20% of annual household income [16, 17].

However, while there have been previous assessments of TB patient costs in LMICs [18] (including in Ghana, [19]), most studies did not report costs as a proportion of income, nor did they measure affordability of TB care [14]. To enhance the evidence base on the costs and affordability of TB care, WHO developed a survey tool to enable rigorous measurement of TB patient costs and their share of household income [20].

Here, we report findings from a nationwide representative sample of TB patients in Ghana, the first study to use this survey tool in sub-Saharan Africa (SSA). This paper examines the level and composition of costs incurred by TB-affected households during care seeking and treatment, by MDR status; assesses affordability of TB care using catastrophic and impoverishment measures; and describes coping strategies used by TB-affected households to pay for TB care.

Methods

Study setting

Despite positive economic growth over the past two decades and consequent reduction in poverty levels [21], 24.2% of people in Ghana still live below \$1.90/day and economic and health inequalities persist and have worsened [22].

TB incidence in Ghana was estimated at about 160 per 100 000 population in 2016 [2]. A prevalence survey was conducted in 2013, which also highlighted barriers to accessing and adhering to TB care. Diagnostics and treatment for TB are officially offered free of charge by public providers to all presumptive patients and individuals diagnosed with TB disease, with the exception of chest radiography [23].

Data collection

In late 2016, we conducted a nationally representative survey with random cluster sampling among TB patients at health facilities within the National TB Programme network, using an adapted and expanded version of the WHO patient cost tool. 25 districts (clusters) across Ghana were sampled using a probability proportional to size approach, where each district's chance of being selected was relative to the number of TB patients notified in that district in 2015.

Eligibility for the study was restricted to TB patients registered for treatment, attending a health facility within a sampled cluster, who had received at least two weeks of intensive or continuation phase treatment, and who consented to the study. In total, 734 individuals were interviewed; of these, 691 (94%) were eligible and consented to take part in the study. We collected information on TB-related costs incurred by respondents, as well as on their clinical, demographic and socio-economic characteristics.

Costs incurred by TB affected households

The survey collected data on direct medical (consultation fees, drugs, laboratory tests) and non-medical (e.g. transport and food) costs, and indirect costs (the time lost by a patient seeking and receiving care), up to the time of interview. To value time, we employed the output-related approach, by which the value of time is defined as the difference in household annual income pre and post-TB diagnosis [24]. To minimise recall bias, data were collected only for the treatment phase the patient was in at the time of interview (i.e. intensive or continuation phase).

To estimate patient costs for the entire TB episode, including costs for all phases of treatment, we extrapolated costs based on data from patients in other phases of illness. We used the approach recommended by WHO, whereby missing cost data were replaced by the median cost of the phase of illness among those in that phase with available data [20].

Affordability of TB care

We computed four summary metrics of affordability of health care: (i) the *catastrophic payment headcount*, (ii) *catastrophic payment gap*, (iii) *impoverishment incidence* and (iv) *poverty gap* [25].

For the *catastrophic payment headcount ratio*, consistent with the approach adopted by WHO for the 'zero TB-affected families facing catastrophic costs due to TB' indicator, costs were defined as 'catastrophic' if a household incurred total TB-related costs (direct and indirect) exceeding 20% of their pre-disease annual household income [20]. The *catastrophic payment gap* represents the amount by which households exceed this threshold [26].

The *impoverishment incidence* measures the increase in poverty resulting from households incurring costs for TB care. The World Bank US\$ 1.90/day international poverty line is used in this study [27]. The *poverty gap* is the short-fall from this poverty line [28].

Income was measured as self-reported individual and household income where available ($n = 553$). If missing, income estimates were based on self-reported household assets (e.g. composition of floor or ownership of a mobile phone) using a regression-based approach ($n = 134$) [20] (Appendix S1), or minimum reported income where only one asset was reported ($n = 4$). Metrics were computed using the best available measure of income for each household.

We used a Pen's parade chart to plot two income distributions (gross income and income net of payments for TB) using a cumulative proportion of individuals ranked according to their gross household income, to show the potential decrease in household welfare due to payments for TB care and consequent reduction in household income [29].

Coping mechanisms

We also computed a complementary metric ('*coping*') if households undertook any of the following: borrowing (having taken a loan), selling household items or assets (e.g. livestock), and use of savings.

Data analyses

We report descriptive analysis of the level (median and interquartile range, IQR) and composition of costs. We used median values of costs and time as opposed to means due to the skewed distributions of both costs and time spent seeking care. Given the higher costs reported in previous studies for MDR-TB *vs.* drug susceptible (DS) patients, results are presented by MDR status [14, 15].

Comparisons between costs for DS and MDR patients were made using chi-square and Wilcoxon Rank Sum test. All analyses were run in Stata v13.0 (StataCorp, College Station, TX). Costs were converted to United States Dollars (US\$) using the average annual exchange rate during study enrolment of US\$1 = 4.15 Ghanaian cedis (oanda.com).

Sensitivity analyses

For estimating missing costs, we employed a regression-based approach, by estimating costs for that patient and treatment phase using a set of variables conceptually linked to incurring costs (gender, age, occupation, rural/urban residence). We also varied the 20% threshold for catastrophic costs to see how this would affect the proportion of households deemed as facing catastrophic costs. Additional thresholds we considered were 10%, 40% and 50% that have been previously used in the

healthcare literature [30–33]. The catastrophic payment headcount was also computed using consumption expenditure instead of income as a robustness check [34], because in settings where employment is mainly outside the formal sector, consumption expenditure is often believed to be a more valid measure than income [35–37]. Finally, we also looked at how taking into account only direct costs would impact on the proportion of households confronting financial catastrophe.

Ethics

The study was approved by the research ethics committees of the London School of Hygiene and Tropical Medicine (REF:11240) and Ghana Health Service (GHS-ERC 14/06/16).

Findings

Half the sampled patients had a secondary level education and were non-salaried employees (Table 1). Three-quarters of respondents lived in an urban setting. Sixty-six (9.6%) respondents were being treated for MDR-TB at the time of survey, and about a tenth had already been treated for TB in the past (Table 1). Ninety respondents were new cases in their intensive phase of treatment and reported on average a delay of four weeks between experiencing symptoms and diagnosis. The characteristics of DS and MDR patients did not differ significantly overall, although DS patients were more likely to be newly diagnosed and have larger household size.

Costs incurred by TB affected households

The median (IQR) costs that TB patients incurred as a result of TB was US\$ 455 (159.2–1059.2). MDR-TB patients incurred significantly higher costs than DS patients: the median expenditure for DS-TB patients was US\$ 429.6 (154.0–981.2), and for MDR-TB patients was US\$ 659.0 (93.2–1680.3) (P -value = 0.001).

Costs after diagnosis were most significant at 93% of total. This was largely driven by non-medical costs, notably income loss (42% for DS and 49% for MDR patients). Median lost income was US\$ 0.0 (0.0–195.2) for DS patients and US\$ 0.0 (0.0–216.9) for MDR-TB (P -value = 0.38). The median percentage of household income lost due to TB was US\$ 0.0% (0.0–14.6%) for DS and US\$ 0.0% (0.0–14.2%) for MDR-TB patients (P -value = 0.43).

Although there was no difference in median costs between DS and MDR before diagnosis, the median costs after diagnosis were almost three times greater for the

Table 1 Descriptive statistics and selected socio-demographic and economic characteristics of the study population, by MDR status and overall

| Characteristic | DS-TB <i>n</i> = 625 | MDR-TB <i>n</i> = 66 | <i>P</i> -value | All <i>n</i> = 691 |
|-----------------------------------------------------------|-------------------------|-------------------------|-----------------|-----------------------|
| Gender, <i>n</i> (%) | | | | |
| Male | 423 (67.7%) | 42 (63.6%) | 0.51 | 465 (67.3%) |
| Female | 202 (32.3%) | 24 (36.4%) | | 226 (32.7%) |
| Age in years, median [IQR] | 41 [29–52] | 43 [29–50] | 0.88 | 41 (29–52) |
| Phase, <i>n</i> (%) | | | | |
| Intensive | 210 (33.6%) | 22 (33.3%) | 0.10 | 232 (33.6%) |
| Continuation | 415 (66.4%) | 44 (66.7%) | | 459 (66.4%) |
| Recorded HIV status, <i>n</i> (%) | | | | |
| Positive | 121 (19.4%) | 8 (12.1%) | 0.78 | 129 (18.7%) |
| Negative | 431 (69.0%) | 32 (48.5%) | | 463 (67.0%) |
| Unknown | 73 (11.7%) | 26 (39.4%) | | 99 (14.3%) |
| Retreatment status, <i>n</i> (%) | | | | |
| New | 560 (89.6%) | 55 (83.3%) | 0.08 | 615 (89%) |
| Retreatment/relapse | 65 (10.4%) | 11 (16.7%) | | 76 (11%) |
| Diagnosis delay (weeks), median (SD) | 4 (16.2) | 6 (12.9) | | 4 (15.9) |
| <i>n</i> (%) | 80 (44.2%) | 10 (52.6%) | 0.48 | 90 (45%) |
| Patient's education status, <i>n</i> (%) | 623 | 66 | | 689 |
| No education | 125 (20.1) | 11 (16.7) | 0.24 | 136 (19.7) |
| Primary school | 122 (19.6) | 8 (12.1) | | 130 (18.9) |
| Secondary school/high school | 350 (56.2) | 42 (63.6) | | 392 (56.9) |
| University and higher | 26 (4.2) | 5 (7.6) | | 31 (4.5) |
| Occupation pre-disease (by main categories), <i>n</i> (%) | 525 | 59 | | 691 |
| Salaried | 70 (13.3) | 9 (15.4) | 0.16 | 79 (13.5) |
| Not salaried | 269 (51.2) | 36 (61.0) | | 305 (52.2) |
| Not employed/in school | 186 (35.4) | 14 (23.7) | | 200 (34.3) |
| Place of residence, <i>n</i> (%) | 621 | 66 | | 687 |
| Urban | 444 (71.5) | 47 (71.2) | 0.96 | 491 (71.5) |
| Rural | 177 (28.5) | 19 (28.8) | | 196 (28.5) |
| Household size, median [IQR] | 6 [4;11] | 4 [3;9] | 0.01 | 6 [4;11] |
| Monthly household income in US\$ [IQR]† | 144.6 [79.5–241.0] | 154.7 [96.4–241.0] | 0.34 | 144.6 [84.3–241.0] |

†Pre-TB diagnosis.

MDR group (US\$ 1276 *vs.* US\$ 481, *P*-value < 0.0001), due to higher levels of non-medical costs among the MDR group (Appendix S1: Table S1). Food and/or nutritional supplements outside the patient's normal diet were the largest contributors to non-medical expenses and these were significantly higher for MDR than for DS patients (36% *vs.* 21% of total costs) (Figure 1).

Affordability of TB care

The median percentage of household income spent on TB was 32.3% (IQR: 11.7–61.2%), which was significantly higher for MDR compared to DS patients (48.8% *vs.* 31.3%, *P*-value = 0.0016).

The proportion of patients incurring catastrophic costs at a 20% threshold of annual household income was 64.1% (443/691) (95% confidence interval: 60.5–67.6%) (*catastrophic payment headcount ratio*). This ratio was

estimated at 72.7% (CI: 60.5%–82.3%) for MDR patients *vs.* 63.2% (CI: 59.3%–66.9%) for DS individuals – a difference which was not statistically significant (*P*-value = 0.125).

For the *catastrophic payment gap*, patients overshoot the 20% threshold by an average of 39.2 percentage points overall. This indicator was significantly higher for MDR patients (59.2%) than for DS patients (37.1%) (*P*-value = 0.005).

Payments for TB care led to a significant increase in the proportion of households in the study sample that live below the poverty line (PPP US\$ 1.90/day) (*P*-value < 0.001), from 45.6% before TB diagnosis to 59.8% at the time of the survey (*poverty headcount ratio*). There was no statistical difference between the levels of poverty pre-diagnosis nor of the proportions shifted below the poverty line between MDR and DS patients.

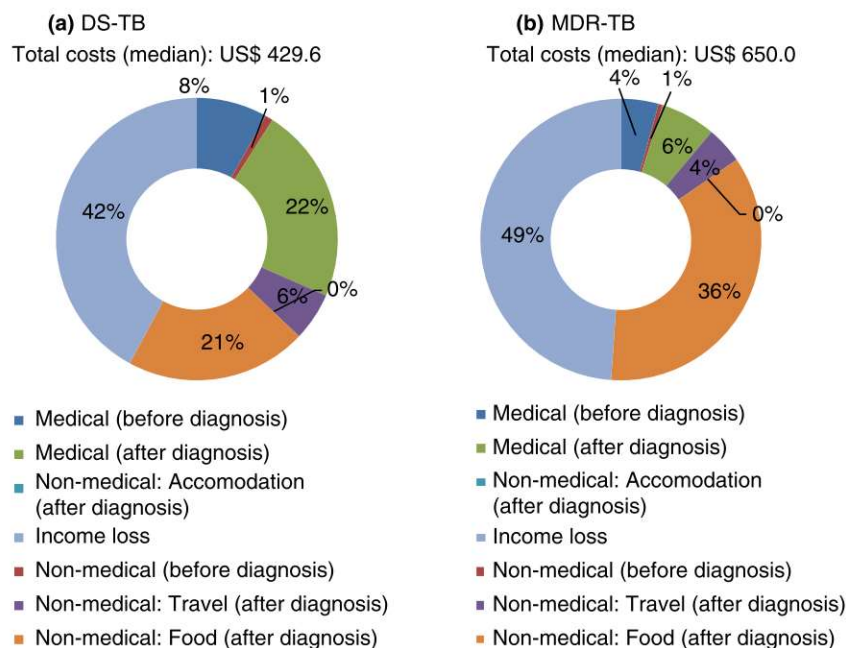


Figure 1 Composition of costs pre and post-TB diagnosis, by MDR status. (a) DS-TB. (b) MDR-TB.

The *poverty gap*, the short-fall from the international poverty line, increased from 60.8% (61.8% for DS and 50.7% for MDR, P -value = 0.012) to 67.0% at the time of survey (68.4% for DS and 56.0% for MDR, P -value = 0.026), a relative increment of 10%, which did not significantly differ by MDR status.

The ‘paint drips’ in the Pen’s chart suggest that payments for TB care led to a decrease in household income and therefore to a decrease in household welfare. It is primarily households in the middle and lower half of the income distribution that are pushed below the poverty line or further into poverty by payments for TB (Figure 2).

Coping mechanisms

Over half (51.5%) of patients were unable to pay for TB-treatment from existing income alone, and had to rely on savings, borrowing or selling assets (collectively termed: coping strategies) to pay for TB-related care (Table 2). This did not significantly differ by MDR status (P -value = 0.4).

Productivity loss

Nearly three-quarters (73.7%) of patients lost days of work due to TB diagnosis and treatment, and this proportion was significantly higher for DS patients (75.3%) than for MDR patients (59.7%) (P -value < 0.008). The median number of working days of income lost was 54

(IQR: 0–150), and this was significantly higher for DS patients (56 days; IQR: 1–150) than for MDR patients (24.5 days; IQR: 0–90) (P = 0.008). The median number of days lost by patients in the formal sector was 30 (IQR: 0–120), *vs.* 60 days (IQR: 14–150) for patients in the informal sector. 41.0% of patients reported that they lost their job as a result of TB. This was not significantly different by MDR status (P -value = 0.186).

Sensitivity analyses

Using the regression-based approach to impute costs instead of the median cost approach, the level of costs incurred decreased by 18.2%, leading to lower estimates of catastrophic costs which significantly differed by MDR status (53.1% for DS and MDR 72.7%; P -value = 0.002) (Appendix S1: Tables S2 and S3). When we used annual household consumption expenditure instead of income, the proportion of households incurring catastrophic costs was fairly consistent (61.8%) and the difference between DS and MDR patients remained statistically insignificant (61.2% *vs.* 67.7%, P -value = 0.305).

As the income threshold increases, the catastrophic payment headcount ratio decreases accordingly, but even at a 40% threshold of annual household income 42.3% of patients would be still considered to incur catastrophic costs (Appendix S1: Figure S1). This ratio was

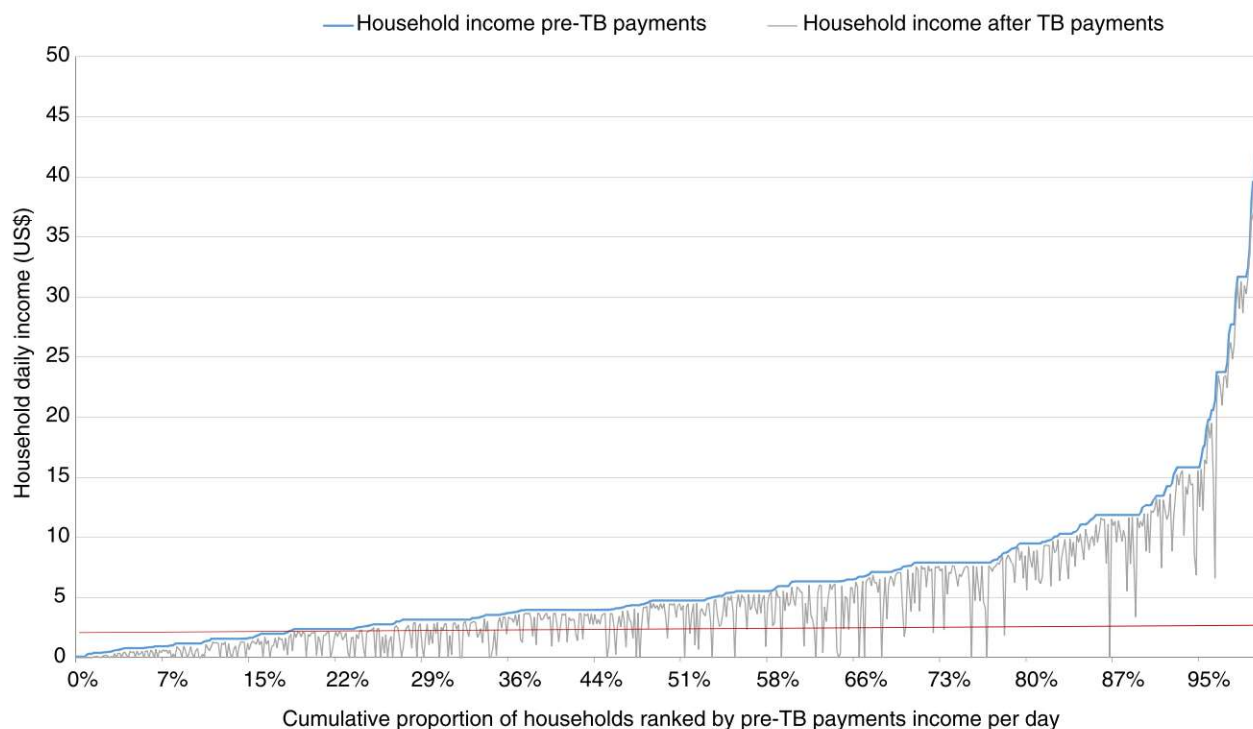


Figure 2 Pen's parade of household income gross and net of payments for TB (red line represents the poverty line at US\$ 2.02 PPP (2015)*). *US\$ 2.02 PPP (2015) = US\$ 1.90 PPP (2011), which is equal to 2.79 Ghanaian cedis (December 2016, oanda.com).

Table 2 Reported dissaving mechanisms by MDR status

| Coping strategies | DS, % (n) | MDR, % (n) | All, % (n) |
|------------------------|----------------|--------------|----------------|
| Loan | 27.0 (169/625) | 30.3 (20/66) | 27.4 (189/691) |
| Use of savings | 29.4 (184/625) | 16.7 (11/66) | 28.2 (195/691) |
| Sale of assets | 10.7 (67/625) | 15.2 (10/66) | 11.1 (77/691) |
| Any of the three above | 52.0 (325/625) | 47.0 (31/66) | 51.5 (356/691) |

significantly different for DS and MDR patients (40.6% *vs.* 57.6%, *P*-value = 0.008).

When we took into account only direct costs in the numerator, 49.1% of patients incurred financial catastrophe, and the difference between DS and MDR patients was significant (47.6% for DS and 63.6% MDR, *P*-value = 0.013).

Discussion

Our findings show that despite policies of free TB care in the public sector in Ghana, TB patients lack financial

protection, with two-thirds of TB-affected households facing financial catastrophe, an additional 14.2% pushed into poverty due to the disease, and half undertaking coping strategies to finance costs. The increase in the poverty gap means that not only is the number of TB-affected households in Ghana that experience catastrophic health payments high, but these households (and especially MDR affected families) also substantially exceed this threshold.

Median costs that TB patients incurred in Ghana are higher than what was found in the systematic review by Tanimura *et al.* (US\$ 379), and in a previous study conducted by Mauch *et al.* in two regions of Ghana in 2009 (US\$ 202) [14, 19]. Although it is hard to directly compare our findings to those from these studies due to the different methodologies employed, it is possible to draw similar conclusions pointing to the financial catastrophe and impoverishment faced by TB patients in Ghana due to TB.

The proportion of TB patients living below the poverty line is greater than in the general population (45.6% *vs.* 24.2%) [38]. This means that TB patients are more vulnerable and policies that can effectively defray costs incurred by TB patients are warranted. As direct medical

expenditures only account for 18.2% of total costs, universal health coverage is unlikely to impact on the number of families facing catastrophic costs. Income loss and food and/or nutritional supplements are the largest cost components. This calls for social protection interventions aimed at income replacement or food assistance programmes, such as the provision of food packages, specifically targeting TB patients [39].

Findings from our study clearly show that to address the devastating economic burden of TB care on TB-affected households, multi-sectoral actions are needed. Eliminating direct medical cost requires thorough review of TB service delivery including streamlined access to quality TB diagnostics and care. To mitigate direct non-medical costs and indirect costs, social support and protection measures need to be enhanced and integrated with TB care. As many patients lost their job as a result of TB, labour protection for TB patients needs to be endorsed and implemented effectively.

Costs incurred pre-diagnosis only account for 7.0% of total costs. The difference in costs between DS and MDR lies primarily in post-diagnosis costs. This is consistent with other surveys that followed the WHO methodology [40], but considerably differs from the findings from the systematic review by Tanimura *et al.* [14], where costs incurred before treatment initiation represented half of total costs. This is likely due to the fact that studies included in this review employed heterogeneous data collection methods. It can also be argued that TB programmes may now be able to link people to care earlier by, for example, further decentralising diagnostic facilities or implementing more systematic case finding activities. This would lead to lower pre-diagnosis costs.

As in previous studies, we found that MDR patients face substantially higher costs than DS-TB which is driven by non-medical expenditures. While there was no statistical difference in the proportion of patients incurring catastrophic expenditures by MDR status, MDR patients were pushed significantly further over the threshold for catastrophic payments than DS patients. To our knowledge, this is the first study to find this. However, when the numerator for catastrophic expenditures is limited to direct costs as is the case conventionally for financial protection measurement, the MDR patients were more likely to incur catastrophic expenditures than DS patients. The impoverishing effects of the disease did not significantly differ by MDR status. The long-term care of the disease makes this group particularly at risk of catastrophic costs and this requires special consideration in TB control programming.

Furthermore, though the evidence on the effects of costs on TB treatment outcomes remains scanty, it may

be reasonable to assume that higher costs associated with seeking and adhering to treatment may lead to worse outcomes by reducing household resources available for food and worsening living conditions. Therefore, the importance of assessing costs may also be clinically relevant.

This study has several limitations. Firstly, it only focused on Ghana, which has low HIV and MDR prevalence, hence our estimate of TB-related costs may be lower compared to other SSA settings with higher TB-HIV and MDR rates. Second, this survey was conducted in health facilities in the National Tuberculosis Programme network, in line with the WHO protocol; however, the 2013 prevalence survey found that 38.5% of patients in Ghana seek care at private facilities. As we do not know if these patients are wealthier or poorer than those in the general population [41], we cannot determine whether the exclusion of the private sector has led to overestimating or underestimating TB-related costs.

In addition, the prevalence survey found little evidence to suggest strong geographical heterogeneity. If the TB epidemic is truly generalised, then districts with low notification rates can be a sign that cases are either not seeking care when needed, have limited access (perhaps geographically) to healthcare or are seeking care, but are being missed by the health system. Our findings may underestimate costs because we overlooked the financial impact on individuals that forgo medical care because they cannot afford to pay (e.g. to reach the health facility). This is a limitation of the sampling methodology which tends to select districts with high notifications and, therefore, possibly with better off patients.

This was a cross-sectional study. A major limitation to the estimation of costs incurred by patients is recall bias, i.e. patients not accurately remembering the amount of time or money they spent in seeking care for their TB diagnosis and treatment. We attempted to minimise recall bias by asking patients only about the treatment phase they were in, and extrapolating costs to the entire episode using two different approaches. While this assumes that every patient successfully completes treatment, it is difficult to determine how patients who fail and/or re-start treatment or die while being treated affect our estimates of costs. We found some sensitivity based on the regression-based approach, but this did not affect the main findings and still meant that over half the respondents face financial catastrophe. This remained true when we considered only direct costs. Finally, this analysis only focuses on the one period consequences of TB, but the effects of coping mechanisms, and the impoverishing and catastrophic consequences of the disease for the

household span well beyond the TB episode by reducing labour supply and productivity.

Conclusions

Although TB diagnosis and treatment are provided free of charge, TB patients in Ghana incur substantial costs and lack financial protection. As non-medical and indirect costs account for the majority of these costs, free TB care is clearly not enough. High rates of catastrophic costs and coping in both non-MDR and MDR patients show that new policies beyond providing free TB care are urgently needed to offset non-medical and indirect costs, and ensure TB care is actually affordable for TB patients. It is therefore essential that countries undertaking TB patient cost surveys follow up on the survey findings by conducting, for example, national consultations with key stakeholders to discuss policy and practice implications, and effectively translate these findings into concrete action.

Acknowledgements

We would like to express our gratitude to the TB patients who took part in the study, and to staff at the health facilities who took the time from their busy schedules to help. We would like to extend a special thanks to researchers at Dodowa Health Research Centre, and staff at Ghana's National Tuberculosis Programme. We wish to thank Katharina Kranzer (London School of Hygiene and Tropical Medicine) for her valuable advice during the preparation of this work, and Nobuyuki Nishikiori (Global Tuberculosis Programme, World Health Organization) for his insightful comments on the manuscript and his work on translating findings from this study into policy action. This study was made possible by the generous support of the American people through the United States Agency for International Development (USAID) through the TREAT-TB grant (GHN-A-00-08-000400). AS is a staff member of the World Health Organization.

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D. Pedrazzoli *et al.* **How affordable is TB care in Ghana?**

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article:

Appendix S1: Prediction of household annual income based on asset ownership/dwelling characteristics.

Figure S1. Sensitivity analysis of catastrophic costs threshold.

Table S1. Summary of costs before and after diagnosis, by MDR status and overall.

Table S2. Sensitivity analysis (regression-based method): Summary of costs before and after diagnosis, by MDR status and overall.

Table S3. Sensitivity analysis (regression-based method): Catastrophic payments due to TB at the 20% threshold, by MDR status and living standard measure employed.

Corresponding Author Debora Pedrazzoli, Department of Infectious Disease Epidemiology, London School of Hygiene and Tropical Medicine, Keppel Street, London WC1E 7HT, UK. E-mail: debora.pedrazzoli@lshtm.ac.uk