

Free tuberculosis diagnosis and treatment are not enough: patient cost evidence from three continents

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SUMMARY

SETTING: The National Tuberculosis Programs of Ghana, Viet Nam and the Dominican Republic.

OBJECTIVE: To assess the direct and indirect costs of tuberculosis (TB) diagnosis and treatment for patients and households.

DESIGN: Each country translated and adapted a structured questionnaire, the Tool to Estimate Patients' Costs. A random sample of new adult patients treated for at least 1 month was interviewed in all three countries.

RESULTS: Across the countries, 27–70% of patients stopped working and experienced reduced income, 5–37% sold property and 17–47% borrowed money due to TB. Hospitalisation costs (US\$42–118) and addi-

tional food items formed the largest part of direct costs during treatment. Average total patient costs (US\$538–1268) were equivalent to approximately 1 year of individual income.

CONCLUSION: We observed similar patterns and challenges of TB-related costs for patients across the three countries. We advocate for global, united action for TB patients to be included under social protection schemes and for national TB programmes to improve equitable access to care.

KEY WORDS: tuberculosis; Dominican Republic; Ghana; Viet Nam

THE CONNECTION between tuberculosis (TB) and poverty is well established.¹ TB patients face a number of barriers in seeking diagnosis and treatment, including financial costs related to charges for health services, transportation, accommodation, nutrition, and lost income, productivity and time.^{1–3} These barriers cause delays in seeking health care, resulting in more advanced disease and continued transmission of TB.⁴ Direct out-of-pocket costs for public or private services and indirect opportunity costs can trigger a spiral into deeper poverty for TB patients and their families.⁵ A number of studies have been published on patient costs in developing countries;^{6–17} however, comparisons of study results are difficult due to the different tools employed. To date, comparative studies on patient costs have mainly been conducted in Western countries.^{18,19} Our aim was therefore to assess whether similar patterns in cost burden can be found in different settings using the same cost-

assessment tool and closely involving the national TB programmes (NTPs).

The main objective of the present study was therefore to evaluate the direct and indirect costs of TB patients on three continents before/during diagnosis and during treatment using the Tool to Estimate Patients' Costs,²⁰ which has been described elsewhere in detail.²¹ We also aimed to identify relevant interventions to reduce patient costs in each country. This article describes the key results of the implementation of the tool in Ghana, Viet Nam and the Dominican Republic, and the resulting recommendations and interventions.

STUDY POPULATION AND METHODS

Setting

All three countries studied follow the World Health Organization (WHO) recommended DOTS strategy

for TB control. While basic TB diagnostics (sputum smear microscopy) and treatment (first-line TB drugs) are provided free of charge, X-rays and hospitalisation are charged in all countries. With an estimated population of 24 million in 2010, Ghana notified 14 607 TB patients in 2010 and treated 87% of patients notified in 2009 successfully.²² The Dominican Republic had an estimated population of 10 million in 2010, with 3964 TB patients notified in 2010; 85% of patients notified in 2009 were successfully treated.²² Compared to the other countries, Viet Nam had the largest population, with 88 million (2010), and the largest number of TB patients ($n = 94\,867$). Viet Nam treated 92% of its TB patients notified in 2009 successfully.²² Ghana is the poorest country among the three (Human Development Report Index Rank 135), followed by Viet Nam (rank 128) and the Dominican Republic (rank 98).²³

Methods

Each country adapted and translated the generic questionnaire,²¹ based on local circumstances (NTP, economy, culture, language, social values and norms). In Ghana, the questionnaire was translated into English, Twi, Ga, Kassim, Nankam and Frafra. Interviews took place in two purposively selected regions: Eastern, a wealthier region, and Upper Eastern, a more deprived region. Urban and rural areas were included. Of 242 patients registered at all 25 public health facilities in both regions, 159 were interviewed either at the health facility or at home. Due to inclusion of retreatment patients in the interviews and their exclusion from the analysis, complete information was available for 135 patients.

In Viet Nam, the questionnaire was translated into Vietnamese. Three provinces were purposively selected: Hanoi, Quangnam and Binh Duong. In each province, two districts were randomly selected, one urban and one rural. Interviews were conducted at six public sector sites. Of 300 randomly selected patients recorded at selected facilities, all 300 were interviewed. As retreatment patients were included in the interviews but excluded from the analysis, infor-

mation is available for 258 patients. Due to the sensitive nature of questions on costs and payments, as well as some challenges faced in interviewer training, not all questions were answered by all patients, resulting in fewer total records for some sections.

In the Dominican Republic, the questionnaire was translated into Spanish. Interviews took place at 32 randomly selected facilities in three purposively selected provincial health directorates, Santiago, La Vega and San Cristobal, and three health area directorates, Areas IV, V and VIII. These included urban and rural areas and public and private sector institutions. A total of 150 new patients who visited the selected facilities on the days of the survey were interviewed.

All countries back-translated the questionnaire to ensure accuracy of translation, pre-tested the questionnaire with adjustments made as needed, and received approval from the appropriate ethical review committees. All participants in the studies provided informed consent (written consent in Ghana and the Dominican Republic and oral consent in Viet Nam). All interviews took place with patients on treatment for at least 1 month. Table 1 provides an overview of the methodologies employed in each country. All three countries followed the tool guidelines for calculating costs;²¹ indirect costs were calculated as income lost due to TB. For income lost prior to treatment, time off work was multiplied by the reported individual income prior to the onset of TB. For income lost during treatment, time off work was multiplied by the reported individual income since the onset of TB.

RESULTS

The results for all countries are summarised and compared in Tables 2–5. Factors related to local circumstances and health systems differed, such as patient education levels (Table 2), type of facility visited to seek care (Table 3), magnitude of specific costs incurred (Table 4), place of treatment provision, and health insurance coverage (Table 5). The average time to collect drugs, including travel and waiting time, was similar across countries, at about 1 h 20 min (Table 5).

Table 1 Overview of study methodology

	Ghana	Viet Nam	Dominican Republic
Sample population	135	258	150*
Age, years	≥15	>15	18–65
Type of TB patients	New out-patients	New out-patients	New out-patients*
Treatment regimen	All: 2(RHZE)/4(RH)	2S(RHZ)/6(EH) ($n = 245$) 2(RHZE)/6(EH) ($n = 13$)	New ($n = 150$): 2(RHZE)/4(RH) ₃ [†]
Robustness of income data	Assessed	Not assessed	Not assessed

*The team in the Dominican Republic also interviewed retreatment out-patients and MDR-TB patients; however, in this article we present data on new patients only. Results of retreatment and MDR-TB patients have been submitted for publication.

[†]Three times weekly.

TB = tuberculosis; R = rifampicin; H = isoniazid; Z = pyrazinamide; E = ethambutol; S = streptomycin; MDR = multi-drug-resistant TB.

Table 2 Characteristics of study population

	Ghana %	Viet Nam %	Dominican Republic %
Type of TB			
Smear-positive	65	58	69
Smear-negative	26	23	11
EPTB	9	19	20
Place of treatment			
Hospital	72	5	56
Primary care unit (health centre)	21	—	43
Community	6	95	1
Private facility (public- private-mix)	1	—	—
Sex			
Male	61	72	55
Female	39	28	45
Age, years			
15–24	10	9	20
25–44	38	36	54
≥45	47	54	26
Unknown	5	1	—
Education			
Illiterate	38	3	5
Primary school	19	21	80
Secondary school	40	36	1
High school	—	29	—
College/university	30	10	14
Unknown	—	1	—
HIV status			
HIV-positive	22	4	11
HIV-negative	67	57	66
Not known	11	39	23

TB = tuberculosis; EPTB = extra-pulmonary TB; HIV = human immunodeficiency virus.

Factors related to the impact of TB on the welfare of individuals and their households are similar across the three countries. A substantial percentage of TB patients had to stop working due to TB (70% in Ghana, 27% in Viet Nam, 60% in the Dominican Republic) and therefore experienced reduced income (Table 5). In all countries (Table 5), nearly a third of all patients were hospitalised at some stage for TB, incurring enormous (mean) costs (Table 4), equivalent to 67% of monthly individual income in Ghana, 149% in Viet Nam and 34% in the Dominican Republic.* Furthermore, many interviewed patients sold property (37% in Ghana, 5% in Viet Nam, 19% in the Dominican Republic) or borrowed money (47% in Ghana, 17% in Viet Nam, 45% in the Dominican Republic), affecting future welfare and socio-economic status.

The main direct cost items before and during TB diagnosis in all three countries were drugs and tests that were not directly related to TB diagnosis and treatment (Table 4). Hospitalisation costs and additional food items form the largest part of direct costs during treatment.

*Applicable to individuals with a monthly income of >US\$166 before onset of disease, see also Table 5.

Table 3 Health care seeking behaviour

	Ghana %	Viet Nam %	Dominican Republic %
Type of facility visited			
Regional hospital	—	35	21
District hospital	43	11	23
Private clinic	1	17	23
Primary care unit	28	12	23
Pharmacy	—	1	1
Others	28*	24	9
Symptoms and delay [†]			
Cough	88	73	83
Fever/chest pain/cold	53	54	82
Weight loss	51	45	78
Haemoptysis	14	13	23
Night sweats	51	9	46
Mean delay, weeks	7	NA	6

* Mission hospital.

[†] In presenting to a facility with TB diagnostic services.

NA = not available.

Health care seeking behaviour

In all three countries, more than 40% of patients visited hospitals during care seeking, and a considerable number in Viet Nam and Ghana visited private clinics (Table 3). In Viet Nam and the Dominican Republic, those patients who visited non-public facilities were asked for their reasons for doing so. In Viet Nam, 21% cited distance as the main reason and 29% mentioned waiting times; 46% reported other reasons such as habit or convenience. In the Dominican Republic, 27% cited mistrust of public services as the main reason, while 23% mentioned obtaining private health insurance; 16% mentioned distance as the main reason. Men prolonged health care seeking for the same symptoms by on average one more week than women. In Ghana and the Dominican Republic, the mean patient delay from experiencing symptoms to seeking care at a facility offering TB services was quite similar (7 and 6 weeks, respectively). In Viet Nam, data on this are not available, as the question was not well understood by the interviewers, and non-response was very high.

Comorbidities

In the Dominican Republic, 26% of TB patients had chronic comorbidities other than human immunodeficiency virus (HIV) infection such as diabetes, high blood pressure and arthritis. In Viet Nam, 40 TB patients (15.5%) were also treated for other diseases, of whom 4% were HIV-positive. Patients treated for other diseases in addition to TB incurred a mean additional cost of US\$37. In the Dominican Republic, 30% of HIV-positive TB patients were on antiretroviral therapy. HIV-positive TB patients in the Dominican Republic had more direct (+US\$2) and indirect (+US\$600) costs than HIV-negative patients due to more health facility visits. However, HIV-negative patients had higher costs due to hospitalisation

Table 4 Summary of direct and indirect patient costs, US\$*

	Ghana			Viet Nam [†]			Dominican Republic		
	Mean	Median [IQR]	n (%) [‡]	Mean	Median [IQR]	n (%) [‡]	Mean	Median [IQR]	n (%) [‡]
Subtotal direct pre-/diagnosis costs	31	14 [4–39]	135 (100)	92	8 [10–87]	193 (75)	38	8 [2–19]	149 (99)
Administrative charges	3	0 [0–4]	135 (100)	8	2 [1.8–5.0]	40 (16)	14	0 [0–0.8]	148 (99)
Non-TB tests	1	0 [0–0]	135 (100)	47	9 [4.1–47.1]	67 (26)	6	0 [0–0.4]	127 (85)
X-rays	3	0 [0–3]	135 (100)	11	3 [1.8–5.9]	108 (42)	17	0 [0–5.5]	125 (84)
Non-TB drugs	12	4 [0–14]	135 (100)	26	12 [5.9–26.5]	51 (20)	2	0 [0–4.2]	117 (78)
Transport	4	1 [0–4]	135 (100)	6	2 [1.2–3.5]	130 (50)	2	0.8 [0.6–2.8]	133 (89)
Food	6	1 [0–4]	135 (100)	27	3 [1.2–29.4]	38 (15)	2	0.6 [0–1.4]	114 (77)
Accommodation	2	0 [0–0]	135 (100)	32	29 [8.8–58.8]	3 (1)	0	0 [0–0]	21 (14)
Subtotal direct treatment costs	114	18 [5–52]	135 (100)	73	22 [10–64]	245 (95)	110	12 [5–27]	140 (93)
Hospitalisation	42	16 [0.1–46]	135 (100)	118	44 [28–61]	58 (22)	94	0 [0–1.7]	49 (33)
Food	17	11 [3.3–21.3]	135 (100)	22	12 [8.8–17.6]	218 (84)	21	8 [0–41.6]	25 (57)
Total costs for:									
DOT visits	27	0 [0–25]	135 (100)	18	8 [4–12]	68 (26)	5	4 [2.2–6.7]	130 (87)
Follow-up test visits	1	0 [0–0]	130 (96)	5	3 [2–6]	90 (35)	18	8 [1.2–18.4]	7 (5)
Drug collection visits	27	2 [0–9.4]	135 (100)	1	0.6 [0.6–1.2]	118 (46)	5	4 [2.2–6.9]	128 (85)
Sum of subtotals direct costs	145	32		165	30		148	20	
Subtotal indirect pre-diagnosis costs	381	170 [43–340]	135 (100)	830	721 [478–1029]	51 (20)	1051	666 [275–1186]	112 (75)
Inability to work	381	170 [43–340]	135 (100)	830	721 [478–1029]	51 (20)	1051	666 [275–1186]	112 (75)
Subtotal indirect treatment	12	0 [0]	135 (100)	26	7 [3–12]	165 (64)	69	56 [20–79]	137 (91)
Hospitalisation	8	0 [0–4.4]	135 (100)	92	43 [15–123]	35 (14)	57	48 [21.2–78.2]	118 (79)
Drug collection visits	1	0 [0–0.4]	135 (100)	1	0.4 [0.2–0.8]	141 (55)	2	2 [1–4.6]	125 (84)
DOT visits	3	0 [0–2.9]	135 (100)	3	3 [2–5]	165 (64)	6	3 [1.1–9.0]	117 (78)
Follow-up test visits	0	0	130 (96)	5	2 [1–5]	82 (32)	2	2 [1–4.6]	126 (85)
Sum of subtotals indirect costs	393	170		856	728		1120	722	
Total patient costs (direct + indirect totals)	538	202		1021	758		1268	742	

*Subtotal mean and median numbers were calculated using totals of subcosts from each individual answer; subtotals may therefore differ from the sum of the mean and median individual cost items.

[†]Some patients only provided (sub)total direct costs without specifying individual cost items.

[‡]Percentage of interviewed patients who answered this question (response rate).

IQR = interquartile range; TB = tuberculosis; DOT = directly observed treatment.

Table 5 Financial impact of TB on patients

	Ghana %	Viet Nam %	Dominican Republic %
Patients who stopped working due to TB	70	27	60
Patients who stopped working for more than 6 months	51	26	48
Patients hospitalised for TB	33	23	33
Time spent per drug collection visit	1 h 22 min	1 h 13 min	1 h 20 min
Coping costs			
Patients who sold property	37	5	19
Land	2	21	8
Livestock	44	57	3
Other	54	22	89
Patients who took out loans	47	17	45
At interest >10%	8	7	37
Without interest	84	84	8
Monthly individual income, US\$			
Before onset of TB	62	79	0 (for 1%)*
After onset of TB	10	59	0 (for 54%) [†]
% income change due to TB	84	25	100 (for 54%)
Expenditures on health care as % of monthly household income	108	12	360 [‡]
Patients with health insurance	67	48	32
Patients who received reimbursements	4	26	3

*Data available only in ranges: US\$0 = 1% of interviewed patients; <US\$42 = 8% of interviewed patients; US\$42–83 = 14% of interviewed patients; US\$83–166 = 27% of interviewed patients; >US\$166 = 50% of interviewed patients.

[†]Data available only in ranges: US\$0 = 54% of interviewed patients; <US\$42 = 2%; US\$42–83 = 6%; US\$83–166 = 16%; >US\$166 = 26% of interviewed patients.

[‡]Applies only to the lowest income group (data available only in ranges for income groups, see *).

TB = tuberculosis.

(US\$127 vs. US\$51). Costs during diagnosis and treatment in Ghana were lower for HIV-positive TB patients than for HIV-negative patients (US\$393 vs. US\$793).

Impact of TB

In the Dominican Republic, the proportion of patients with zero income increased from 1% to 54% due to TB (Table 5). The lowest income group, with <US\$42 per month, spent 360% of its monthly household income on health care. In Ghana, the individual mean monthly income dropped by 79% due to TB. The change was particularly acute for women, whose mean monthly individual income changed from US\$57 to US\$3 (men US\$67 to US\$16). Here, TB patients spent 108% of monthly household income on health care. In Viet Nam, household expenditures on food and health care increased by almost 50% due to TB. Expenditures on health care amounted to 12% of monthly household income due to TB. TB patients in Ghana and the Dominican Republic face catastrophic health expenditures, defined by the WHO²⁴ as $\geq 40\%$ of non-subsistence household income. Moreover, the percentage of interviewed TB patients with incomes below the poverty line of US\$1 per day increased in all three countries due to TB (Figure).

In all countries, costs were incurred for a treatment supporter or family member (guardian). These were as follows: Ghana, median US\$26 direct and US\$0 indirect costs; in Viet Nam, median US\$85 direct and US\$0 indirect costs; and in the Dominican Republic median US\$51 direct and US\$66 indirect costs.

DISCUSSION

The mean total direct costs as a percentage of total patient costs were higher in Ghana (27%) than in Viet Nam (16%) and the Dominican Republic (12%) due to higher costs for health facility visits for DOTS and drug collection. The increase in patients with incomes <US\$1 per day due to TB was high in the

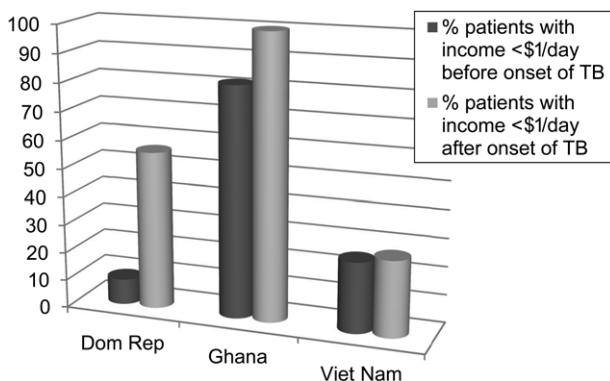


Figure Patients below US\$1/day poverty line before and after onset of TB. TB = tuberculosis.

Dominican Republic, while it was comparatively low in Viet Nam. The latter confirms the findings of van Doorslaer and O'Donnell that Viet Nam relied heavily on out-of-pocket payments but were 'more successful in limiting their impoverishing effect'.²⁵ Total patient costs (including direct and indirect costs) in all countries were equivalent to approximately 1 year of individual income (Table 5). The differences in guardian costs across countries are probably related to the fact that health care facilities in Ghana are further from patients' homes, resulting in higher transport costs and more investment of time.

Recommendations based on the studies in all three countries were similar: bringing services closer to patients, reducing expenditures on transport and invested time, increasing efforts to find cases early to reduce indirect costs related to inability to work, informing health care workers and the public about TB diagnosis and treatment to reduce costs unrelated to TB, and including TB-related out-patient costs in social protection schemes.

Following the presentation of the results, each country took action to improve identified bottlenecks. In Ghana, the NTP presented the study findings to the Ministry of Health (MoH). As a result, policy makers agreed to include TB care interventions as part of its pro-poor strategies in the delivery of health care. The Nutrition Department of the MoH has since developed nutrition guidelines to address the specific needs of TB patients. Second, the evidence generated from the study findings was key in informing and developing the successful Global Fund Round 10 TB proposal. Given the identified high burden for female TB patients in Ghana, the NTP is currently focused on addressing gender-sensitive challenges of poor TB patients. Third, the parliamentary sub-committee on health has considerably advanced insurance coverage for all TB patients for health-related costs other than (free) anti-tuberculosis treatment. Lastly, study findings were presented at Union conferences in Lille, France, and Abuja, Nigeria.

As a result of the study, the NTP in Viet Nam is working toward increased involvement of the private sector in public-private-mix projects focusing on reducing travel, accommodation and hospitalisation costs for TB patients and guardians. Second, the study contributed to the decision to switch from the 8-month to the 6-month anti-tuberculosis treatment regimen, which will help reduce the treatment time and travel costs for follow-up tests. Third, the NTP is working on the expansion of its NTP network to provide TB services at provincial general hospitals, all major public non-MoH hospitals and private hospitals. Fourth, the NTP has started planning for a way to provide social and economic support to TB patients in each district. Finally, the NTP has been mobilising support for TB patients by organisations such as farmers and womens' unions.

In the Dominican Republic, the MoH evaluated the study findings in depth and explored the possibilities for implementing the recommendations. In 2011, the MoH moved forward with increased efforts to allocate public funds for food supplements for TB patients and for the inclusion of in- and out-patient TB services in the national health insurance schemes.

In summary, using the tool²¹ provided results pointing towards similar patterns and challenges across the three countries. These triggered similar conclusions and recommendations. TB patients worldwide are in danger of spiralling into deeper poverty. As this effect is not limited to individual NTPs, it requires global action. Together with other research evidence,^{9–14,26} our results strongly suggest that it is time for global institutions to improve social protection for TB patients. In the meantime, NTPs need to minimise costs for patients by providing services that are completely free, decentralising care with appropriate supervision and quality assurance, and improving access to care.

Limitations

All study teams reported difficulties with recall bias and conveying cost and payment concepts to patients. In Viet Nam, several patients could only provide (sub-)total direct costs, without specifying individual cost items (Table 4). Although absolute costs in US\$ are difficult to compare, the relative burden and impact of TB on the welfare of the individual and the household can nevertheless be demonstrated. The costs incurred by TB patients as described here do not directly account for costs of comorbidities, although these additional costs are reflected in the indirect costs and coping strategies. Free TB care is only partly helpful if patients incur additional substantial costs due to comorbidities. We did not investigate whether the financial burden affected treatment completion. We do not intend to compare results closely across these countries, which have very different cultural settings, values, norms, health systems and purchasing power parities; however, the results still indicate that TB patients on different continents face similar catastrophic events unmediated by existing health systems and social protection schemes.

CONCLUSIONS

These results from the Dominican Republic, Ghana and Viet Nam show that patients face very high direct and indirect costs before and during TB diagnosis and treatment, which often translate into catastrophic financial events and increased poverty. It is time for the international community to come together and address the need for greater social protection of TB patients.

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R É S U M É

CONTEXTE : Programmes Nationaux de Tuberculose (PNT) au Ghana, au Viet Nam et en République Dominicaine.

OBJECTIF : Evaluer les coûts directs et indirects du diagnostic et du traitement de la tuberculose (TB) encourus par les patients et les ménages.

SCHEMA : Un questionnaire structuré, le Tool to Estimate Patient's Costs, a été traduit et adapté dans chaque pays. On a interviewé dans les trois pays un échantillon aléatoire de nouveaux patients adultes sous traitement depuis au moins un mois.

RÉSULTATS : Dans les divers pays, 27–70% des patients ont arrêté le travail et ont subi des réductions de revenus, 5–37% ont dû vendre leurs biens et 17–47% ont

dû emprunter de l'argent à cause de la TB. Les coûts d'hospitalisation (US\$42–118) et les compléments alimentaires constituent la plus grande partie des coûts directs au cours du traitement. Les coûts moyens totaux par patient (US\$538–1.268) représentent approximativement le revenu individuel d'une année.

CONCLUSION : Dans les trois pays, nous avons observé des types et défis similaires en ce qui concerne les coûts-patient liés à la TB. Nous plaidons en faveur de l'introduction dans les schémas de protection sociale d'une action mondiale et unifiée en faveur des patients TB ainsi qu'en faveur de l'amélioration d'un accès équitable aux soins à charge des PNT.

R E S U M E N

MARCO DE REFERENCIA: El Programa Nacional contra la Tuberculosis (PNT) de Ghana, Viet Nam y la República Dominicana.

OBJETIVO: Evaluar los costos directos e indirectos del diagnóstico y el tratamiento de la tuberculosis (TB) para los pacientes y los hogares.

MÉTODO: En cada país se tradujo y se adaptó la herramienta de cálculo de los costos para los pacientes, que consiste en un cuestionario estructurado. Se escogió de manera aleatoria una muestra de pacientes nuevos que habían recibido como mínimo 1 mes de tratamiento en los tres países.

RESULTADOS: En todos los países, de 27% a 70% de los pacientes interrumpieron su trabajo y sufrieron una disminución de los ingresos, de 5% a 37% vendieron

propiedades y de 17% a 47% prestaron dinero por causa de la TB. La mayor parte de los costos directos correspondieron a los costos de hospitalización (entre US\$42 y US\$118) y los complementos de alimentación durante el tratamiento. En promedio, los costos de la enfermedad para el paciente (entre US\$538 y US\$1268) fueron equivalentes a los ingresos individuales de 1 año.

CONCLUSIÓN: Se observó que las características de los costos relacionados con la TB y las dificultades que estos generan en los pacientes son análogas en los tres países estudiados. Se recomienda promover una acción mundial y unificada en favor de estos pacientes, en el marco de los programas de protección social y de los PNT, con el fin de optimizar el acceso equitativo a la atención de salud.