# Tuberculosis patients in the Dominican Republic face severe direct and indirect costs and need social protection

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**ABSTRACT**

**Objective.** *To examine direct and indirect costs incurred by new, retreatment, and multidrug-resistant (MDR) tuberculosis (TB) patients in the Dominican Republic before and during diagnosis, and during treatment, to generate an evidence base and formulate recommendations.*

**Methods.** *The "Tool to Estimate Patients' Costs" was adapted to the local setting, translated into Spanish, and pretested. Patients attending 32 randomly selected health facilities in six chosen study areas on the study days were interviewed. Responses from patients 18–65 years old who had received treatment for at least one month and provided signed informed consent were collected, entered into a database, and analyzed.*

**Results.** *A total of 200 patients were interviewed. For most respondents, direct and indirect costs increased while income decreased. Total costs amounted to a median of US$ 908 for new patients, US$ 432 for retreatment patients, and US$ 3 557 for MDR-TB patients. The proportion of patients without a regular income increased from 1% to 54% because of falling ill with TB. Following its review of the study results the Ministry of Health has made efforts to allocate public funds for food supplements and to include in- and outpatient TB services in the national health insurance schemes.*

**Conclusions.** *Free TB diagnosis and treatment are not enough to alleviate the financial constraints experienced by vulnerable groups as a result of the illness. Health insurance covering TB in- and outpatient costs is critical to prevent TB-related financial hardship.*

**Key words** Tuberculosis; tuberculosis, multidrug-resistant; cost of illness; Dominican Republic.

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Tuberculosis (TB) is a major infectious disease associated with poor living standards and the socioeconomically disadvantaged (1, 2). In 2010, 214 030 TB cases were notified in Latin America (total population 933 million), of which 3 964 (1.85%) were in the Dominican Republic (equal to 1.07% of the country's total population of 10 million) (3).[7] In 2007, the Pan American Health Organization (PAHO) (4) reported a rise in out-of-pocket expenses in the Dominican Republic mainly due to low government expenditures on health and a lack of financial security in the form of insurance. While a number of studies on patient costs have been conducted in Africa (5–9), until 2009 little evidence from Latin America was available in the literature

[7] Of the 3 964 cases, 2 159 were notified new smear–positive, 803 new smear–negative, 578 extra-pulmonary, and 424 retreatment and undefined cases. The case notification rate was 40/100 000 population for all cases of TB.

and none of the studies included costs incurred by multidrug-resistant tuberculosis (MDR-TB) patients. Studies done in Peru,[8] Haiti (10), Mexico (11), and the Dominican Republic[9] investigated the economic impact of TB. The study conducted in the Dominican Republic found that the DOTS expansion strategy[10] combined with a patient-centered approach had a positive impact on TB control.

In 2009, the Dominican Republic Ministry of Health and its partners conducted a study to determine the costs that TB patients incur. Direct ("out-of-pocket") and indirect (opportunity) costs of new, retreatment, and MDR-TB patients before and during diagnosis and during treatment were investigated. This was linked to information on patients' socioeconomic status, health-seeking behavior, and HIV status, as well as the impact of TB on the welfare of the household. The study aimed to establish an evidence base upon which recommendations and interventions could be formulated to address identified constraints. For this purpose, the research team decided to use the "Tool to Estimate Patients' Costs," which has been validated and described elsewhere in detail (8) and can be downloaded for free.[11] This article presents the findings of the study and the resulting actions.

In the Dominican Republic, diagnosis (sputum smear microscopy) and treatment for TB is free of charge (including MDR-TB[12]) and is performed according to the DOTS expansion strategy (12). Fees are charged for x-rays. Upon diagnosis, new TB patients follow a six-month treatment regimen (two months of four drugs daily followed by four months of two drugs taken three times weekly). Retreatment patients follow an eight-month regimen (five drugs for two months daily followed by one month of four drugs daily, followed by five months of two drugs taken three times weekly), and MDR-TB patients follow a 24-month treatment regimen (six months of five drugs daily followed by 18 months of two drugs daily). All TB patients are required to take their drugs under observation at health facilities throughout the entire course of treatment.

## MATERIALS AND METHODS

### Study sites

This study was descriptive and cross-sectional. Three provincial health directorates (Santiago, La Vega, and San Cristóbal) and three health area directorates (Areas IV, V, and VIII) comprising both urban and rural areas were purposively selected. Santiago and Areas IV, V, and VIII were chosen because of high TB caseloads (20.7% of the annual national case notification). San Cristóbal and La Vega were included because they have MDR-TB reference centers. Patients attending 32 randomly selected health facilities (public and private) in the six chosen study areas were sampled (Table 1). As this was an exploratory study, a target enrollment of 200 patients was considered a sample size sufficiently powerful for statistical analysis.

### Study population

Interviews were conducted during TB clinic days. The inclusion criteria included being a new, retreatment, or MDR-TB patient, having received treatment for at least one month, and being between 18 and 65 years of age. MDR-TB patients included those who had initiated treatment for at least one month and no longer than three months at MDR-TB treatment sites and were previously treated with a standard retreatment regimen. Every TB patient that attended the selected health facility and fulfilled the above-mentioned inclusion criteria was asked to participate in the study. TB patients who had initiated but stopped treatment ("defaulters"), had a modified regimen due to treatment failure or adverse reactions, or declined to be interviewed were excluded from the study. All patients who agreed to be interviewed signed an informed consent form after being briefed on their rights.

### Questionnaire development and interviewer training

The questionnaire (8) was translated into Spanish, adapted to fit the local context, and pretested in six health facilities representing all study areas. Based on the results of the pretest, the questionnaire was further adapted and back-translated into English to ensure accuracy of translation. Four interviewers were trained in a two-day course. Special attention was given to confidentiality, informed consent, TB infection prevention, economic concepts, and costs. Interviews were conducted in Spanish. The study protocol and questionnaire were approved by the Independent Ethics Review Committee of the Asociación Dominicana Pro-Bienestar de la Familia (Profamilia), a nongovernmental organization (NGO) in the Dominican Republic.

### Data entry and analysis

Completed questionnaires were delivered to the field coordinator and reviewed for completeness. Thereafter questionnaires were coded and data was entered using Epi Info 3.4 (Centers for Disease Control and Prevention, Atlanta, Georgia, USA). Data was double-entered for consistency checks and analyzed using Microsoft Excel (Microsoft, Redmond, Washington, USA) and SPSS 13.0 (SPSS Inc, Chicago, Illinois, USA). Median values were used for quantitative comparison to avoid distortion of results by outliers. Costs were reported in DR pesos (RD$) and converted to U.S. dollars (US$) for analysis. At the time of the study (2009), the exchange rate was RD$ 36.06 to US$1. Costs were distinguished as direct and indirect costs. Direct costs are out-of-pocket costs such as administrative fees, charges for tests and medicines, transport, food, and accommodation. Transport and other costs related to health facility visits were calculated based on the number of trips required for a full course of treatment. Indirect costs included income, productivity, and time lost due to TB. To calculate income lost before the onset of the TB illness, lost working time was multiplied with the median reported individual income before the onset of TB. Pretreatment costs of MDR-TB patients were calculated in the same way as for new TB patients. Income lost during treatment was calculated by multiplying the time off work

[8] Ministerio de Salud (PE). Impacto económico de la tuberculosis en el Perú. Unpublished report 2001.

[9] Acosta I, Marcelino B. Impact of DOTS expansion on TB-related outcomes and cost in the Dominican Republic. Unpublished report 2004.

[10] As defined by the World Health Organization in the Stop TB Strategy (2006), the DOTS strategy includes five elements: 1) political commitment with increased and sustained financing; 2) case detection through quality-assured bacteriology; 3) standardized treatment with supervision and patient support (directly observed treatment, DOT); 4) an effective drug supply and management system; and 5) a monitoring and evaluation system, and impact measurement.

[11] www.tbcare1.org/publications/toolbox/access/ and www.stoptb.org/wg/dots_expansion/tbandpoverty/spotlight.asp

[12] Diagnosis: culture and drug-susceptibility testing are free; any other tests are charged. Treatment: all subscribed medications are free.

**TABLE 1. Socio-demographic, health, and tuberculosis (TB) data, Dominican Republic, 2009**

| Characteristic | Dominican Republic | Santiago | La Vega | San Cristóbal | Area IV (Santo Domingo) | Area V (Distrito Nacional) | Area VIII (Santo Domingo) |
|---|---|---|---|---|---|---|---|
| Estimated population | 9 755 954[a] | 1 031 447[b] | 647 003[b] | 647 003[b] | 500 846[b] | 362 019[b] | 254 931[b] |
| Estimated annual per capita income (US$)[c] | 4 670[a] | 1 679 | 1 580 | 2 035 | –[d] | 1 897 | – |
| Number of TB cases notified[b] | 4 256[e] | 193 | 63 | 141 | 280 | 84 | 47 |
| CNR[f] per 100 000 population | 42 | 21 | 16 | 25 | 58 | 23 | 120 |
| Estimated HIV prevalence 15–49 years (%)[g] | 0.9 | 0.7–0.9 | 0.7–0.9 | 0.5–0.6 | 0.5–0.6 | 0.5–0.6 | 0.5–0.6 |
| Number of TB patients tested for HIV[b] | 397 | 31 | 13 | 20 | 33 | 15 | 18 |
| % HIV positive | 9 | 8 | 14 | 7 | 7 | 8 | 9 |
| Number of public health facilities per 100 000 population[h] | 28 | 13 | 22 | 20 | – | – | – |
| Number of TB treatment centers[b] | 1 068 | 70 | 55 | 75 | 40 | 30 | 18 |
| Number of TB treatment centers per 100 000 population | 10.9 | 6.8 | 8.5 | 11.6 | 7.9 | 8.3 | 7.1 |

[a] Reference 13.
[b] National Tuberculosis Control Program (DR). Annual Report. Unpublished report 2009.
[c] Reference 14.
[d] Data not available.
[e] Reference 15.
[f] CNR = case notification rate.
[g] Reference 16.
[h] Reference 17.

with the median reported individual income since the onset of TB. Health insurance reimbursements were deducted. Interviewees were assigned to income groups according to the 2008 United Nations Development Programme (UNDP) Human Development Report for the Dominican Republic (14).

## RESULTS

A total of 200 individuals were interviewed between 1 July and 30 August 2009. Of those, 98% were patients and 2% were people accompanying the patients ("guardians"). Two interviewees were excluded from the analysis due to incomplete data. No patient or guardian refused or stopped the interview. The majority of interviews (58%) took place in a hospital setting (85% of which were municipal hospitals) (Table 2). Table 3 presents TB-related and socioeconomic information for the study sample population. A total of 54.5% of the study population was male. The majority of respondents were 25–44 years old, 80% had primary education, and 5% were illiterate.

### Health-seeking behavior

Almost 90% of respondents sought initial care in the private or public health care sector, with an almost equal number attending each different type (23% went to private facilities, 23% went to public clinics, and 23% and 21% went to municipal and regional hospitals respectively). Only 1.5% went to a traditional healer and less than 1% visited a pharmacy, but 9% used homemade remedies as their initial care. The main reasons reported by the respondents for not visiting a public health facility when first seeking care were lack of trust in the public health service (27%), distance (16%), and availability of private health insurance (23%). The median delay between onset of symptoms and seeking diagnosis was 6 weeks for men and 4.7 weeks for women.

**TABLE 2. Distribution of interview sites and patients surveyed by study area (three provinces and three health areas) for research on costs incurred by tuberculosis patients (*n* = 198), Dominican Republic, 2009**

| Study area | Number and type of interview sites | Number of patients surveyed (%) |
|---|---|---|
| La Vega | 1 hospital | 4 (2) |
| Santiago | 3 hospitals | 40 (20) |
| San Cristóbal | 3 hospitals | 12 (6) |
| Area IV (Santo Domingo) | 1 community center<br>5 clinics<br>4 dispensaries | 55 (28) |
| Area V (Distrito Nacional) | 4 hospitals<br>4 clinics<br>3 dispensaries | 36 (18) |
| Area VIII (Santo Domingo) | 3 hospitals<br>1 clinic | 51 (26) |
| Total | 32 | 198 (100) |

### Pre-diagnosis and diagnosis costs

**Direct.** Most costs before and during diagnosis for new patients were attributed to medications not related to TB (36%), followed by costs for diagnostic tests not related to TB (21%), x-rays (18%), and administrative costs (18%) (Table 4). X-rays are a costly component among diagnostic tests (9% of direct costs for retreatment patients and 5% for MDR-TB patients). Administrative costs included consultation costs and patient registration. Transportation, food, and accommodation costs constituted a comparatively small burden (7% all together). New patients spent a median of US$ 47 on direct costs. Retreatment and MDR-TB patients spent more out-of-pocket money: on diagnostic tests related to TB (retreat-

**TABLE 3. Characteristics of sample population for research on costs incurred by tuberculosis (TB) patients (*n* = 198), Dominican Republic, 2009**

| Characteristic | No. (%)[a] |
|---|---|
| Gender | |
| Male | 108 (54.5) |
| Female | 90 (45.5) |
| Age (years) | |
| 18–24 | 40 (20) |
| 25–44 | 106 (54) |
| ≥ 45 | 52 (26) |
| Type of TB | |
| Smear-positive | 136 (69) |
| Smear-negative | 22 (11) |
| Extra-pulmonary | 40 (20) |
| Treatment category | |
| New | 150 (76) |
| Retreatment | 28 (14) |
| MDR-TB[b] | 20 (10) |
| Treatment site | |
| Hospital | 111 (56) |
| Clinics and dispensaries | 85 (43) |
| Community | 2 (1) |
| HIV status | |
| Negative | 130 (66) |
| Positive | 22 (11) |
| No test | 19 (10) |
| Results unknown | 27 (14) |
| Education (interviewee) | |
| Illiterate | 10 (5) |
| Elementary school | 159 (80) |
| Secondary school | 1 (1) |
| University | 27 (14) |
| Other | 1 (1) |
| Type of work before TB | |
| All year / regular | 111 (56) |
| Seasonal / part-time | 14 (7) |
| Day-to-day | 32 (16) |
| Other | 6 (3) |
| Does not work | 35 (18) |
| Education (head of interviewee's household) | |
| Illiterate | 8 (4) |
| Primary school | 71 (36) |
| Secondary school | 39 (20) |
| University | 24 (12) |
| Other | 3 (1) |
| Data not available | 53 (27) |

[a] Percentages may not sum to 100 because of rounding.
[b] MDR-TB: multidrug-resistant tuberculosis.

**TABLE 4. Median direct costs incurred by tuberculosis (TB) patients (*n* = 198) by type of patient (new, retreatment, and MDR-TB[a]), Dominican Republic, 2009**

| Direct cost | Type of patient | | |
|---|---|---|---|
| | New | Retreatment (in US$[b])[c] | MDR-TB |
| Administrative fees (consultation costs and patient registration fees) | 8.3 | 1.1 | 22.2 |
| Diagnostic tests | 10.4 | 63.8 | 110.9 |
| X-rays | 7.8 | 10.4 | 8.3 |
| Medication | 16.6 | 34.7 | 10.4 |
| Transportation (round trip) | 1.7 | 1.4 | 1.4 |
| Meals | 1.7 | 1.4 | 1.0 |
| Lodging | 0.0 | 0.0 | 0.0 |
| Insurance reimbursement | 0.0 | 0.0 | 0.0 |
| Subtotal | 46.5 | 112.7 | 154.1 |
| Treatment | | | |
| Monthly visits to health facility for DOTS[d] | 23.3 | 28.6 | 58.2 |
| Monthly visits to pick up medications | 6.2 | 12.5 | 13.9 |
| Monthly follow-up visits | 16.6 | 16.6 | 49.9 |
| Hospitalization | 61.0 | 14.8 | 55.5 |
| Food supplements (average monthly) | 19.4 | 20.1 | 25.0 |
| Insurance reimbursement | 0.0 | 0.0 | 0.0 |
| Subtotal | 126.6 | 92.6 | 202.4 |
| Total co-payments for TB-related health services paid by health insurance holders | 8.3 | 5.5 | 55.5 |
| Total | 181.3 | 210.8 | 412.0 |

[a] MDR-TB: multidrug-resistant tuberculosis.
[b] US$1 = RD$ 36.06 (2009).
[c] Numbers may not sum to subtotals because of rounding.
[d] DOTS: directly observed treatment, short-course.

**TABLE 5. Median indirect costs incurred by tuberculosis (TB) patients (*n* = 198) by type of patient (new, retreatment, MDR-TB[a]), Dominican Republic, 2009**

| Indirect cost | Type of patient | | |
|---|---|---|---|
| | New | Retreatment (in US$[b]) | MDR-TB |
| Loss of income, productivity, and time due to: | | | |
| Inability to work | 660.0 | 180.3 | 2 785.4 |
| DOTS[c] visits | 6.1 | 3.7 | 9.7 |
| Medication pickups | 1.7 | 1.5 | 2.4 |
| Follow-up visits | 2.0 | 1.2 | 2.9 |
| Hospitalization | 56.6 | 34.2 | 345.5 |
| Total | 726.4 | 220.9 | 3 145.9 |

[a] MDR-TB: multidrug-resistant tuberculosis.
[b] US$1 = RD$ 36.06 (2009).
[c] DOTS: directly observed treatment, short-course.

ment, 57% of all costs; MDR-TB, 72%) and medication unrelated to TB (retreatment, 31% of all costs; MDR-TB, 7%). Altogether, retreatment patients spent a median of US$ 113 and MDR-TB patients US$ 154 on direct costs before and during diagnosis. Patients attending nonpublic sites incurred more median direct costs than those attending public sector sites (US$ 53.6 versus US$ 8.3), mainly related to administrative charges, x-rays, and non-TB drugs.

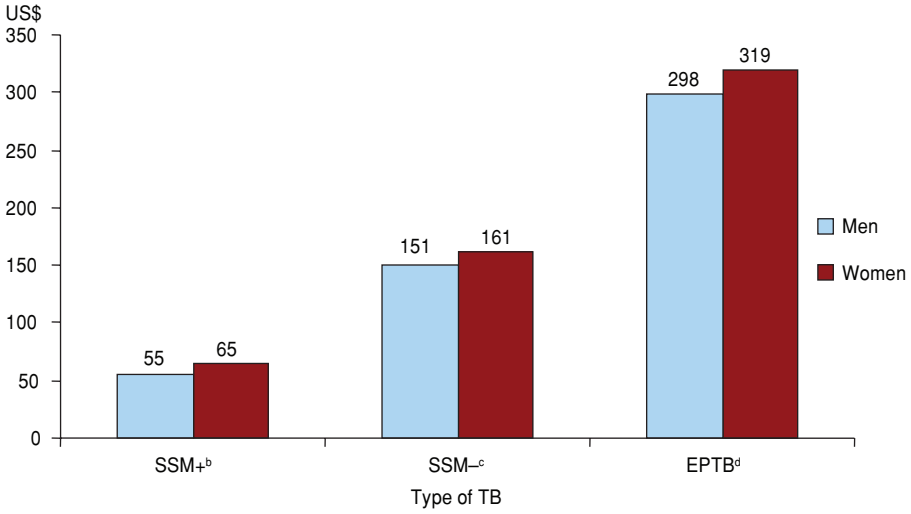
**Indirect.** Indirect costs before and during diagnosis are mainly a result of the inability to work due to the illness. About 60% of respondents stopped working due to TB (Table 5). Of these, 48% stopped for more than six months. There were no significant differences among the respondents with respect to type of TB.

## Treatment costs (including hospitalization)

**Direct.** Patients spent a median of US$ 151 on direct costs during treatment. For those patients who had been hospitalized (33% of all respondents, 65 patients), costs associated with hospitalization accounted for 55% of all direct costs. On average, they were hospitalized for 25 days. Hospitalization costs, which included administrative and bedsheet fees, food, transport, medications, tests, and surgeries, were on average an additional US$ 61 for new patients, US$ 15 for retreatment, and US$ 56 for MDR-TB patients. Women reported higher median costs while hospitalized than men (Figure 1).

Nonhospitalized patients incurred direct costs during treatment mainly for food supplements and transport for treatment (DOTS), to collect TB medi-

**FIGURE 1. Median hospitalization costs[a] incurred by tuberculosis (TB) patients by gender and type of TB, Dominican Republic, 2009**




[a] US$ 1 = RD$36.06 (2009).
[b] SSM+: smear-positive.
[c] SSM–: smear-negative.
[d] EPTB: Extra-pulmonary.

cines, and to conduct follow-up tests or pick up test results. Tables 4 and 5 present direct and indirect costs incurred by new, retreatment, and MDR-TB patients.

**Indirect.** Indirect costs during treatment were high due to inability to work, with a median of US$ 728. Only a small proportion of indirect costs (1%) was associated with time spent on the road to and from health facilities, and waiting time. Median monthly indirect costs for treatment follow-up (DOTS) were US$ 5, for medication collection US$ 1.50, and for follow-up tests US$ 2. On average, it took patients 73 minutes to travel to the health care center, pick up medications, and return home. Hospitalized patients incurred additional median indirect costs of US$ 69, probably due to long hospitalization, severe illness, and therefore longer inability to work.

## Coping costs

To compensate for the high costs they incurred after onset of TB, almost half of all respondents (45%) took up a loan and almost 20% sold property. Loans were mainly provided by family members or friends (80%). Among those paying interest on their loan, 37% paid an annual percentage rate (APR) of more than 10% (a direct cost). Of those respondents selling property, 43% sold household items, 14% sold vehicles, 8% land, and 3% a house. When asked how TB services could be improved to relieve the financial burden of respondents, 65% mentioned food coupons, 15% requested more efficient services, and 6% suggested transport vouchers.

## Guardian costs

About 12% of respondents reported having someone at their home (a guardian) to assist them with care. Guardians are often family members who take time off work for this purpose and therefore incur indirect costs. According to the survey responses, about 75% of TB patients' guardians stayed with them in their homes for more than two weeks. Guardians of new patients incurred a median cost of US$ 117 whereas guardians of retreatment patients incurred US$ 73 and those of MDR-TB patients incurred US$ 176.

## Total costs by treatment category and income group

MDR-TB patients incurred the highest overall costs. Indirect costs were higher than direct costs for all treatment categories (Table 6). Direct costs for new patients were highest during treatment, mainly related to hospitalization. For retreatment and MDR-TB patients, the largest portion of direct costs was attributed to diagnostic tests.

The financial burden is particularly high on the lowest income group. Total costs for those who earn less than US$ 42 per month represent 2 215% of median monthly income. MDR-TB patients are worst off because they incur the comparatively highest costs (8 676%). Except for retreatment patients, indirect costs mean a much higher financial burden than direct costs (approximately four times the direct costs for new patients and seven times for MDR-TB patients). Income groups changed remarkably due to TB (Figure 2). Before falling ill with TB, only about 1% of the study sample did not have a regular income. This proportion increased to 54% after the onset of TB (47% of new patients, 65% of retreatment patients, and 84% of MDR-TB patients).

## HIV and other comorbidities

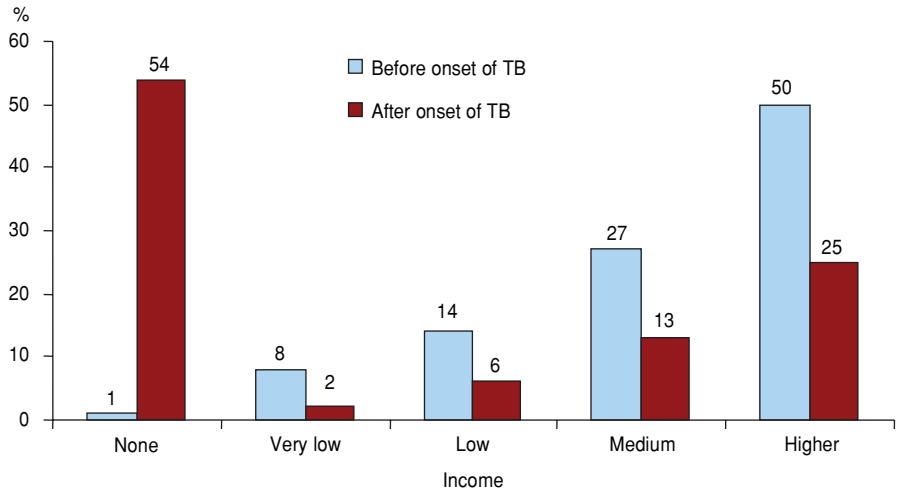
Among the TB/HIV coinfected patients, 29% received antiretroviral treatment (ART) and 20% had other comorbidities such as diabetes, high blood pressure, and arthritis. HIV-positive TB patients incurred higher costs than HIV-negative patients. These higher costs were mainly related to additional visits to the health facility to collect ART medicines and for follow-up treatment. Additional health facility visits resulted in a median of US$ 7 more direct costs and US$ 603 more indirect costs for HIV-positive TB patients. However, HIV-positive patients incurred less total direct costs than HIV-negative patients because they were less often hospitalized and spent less on food and dietary supplements. Reduced spending on food and supplements was mainly due to inability to spend more. When compared by type of treatment, more new patients were HIV positive (12%) than retreatment (11%) and MDR-TB patients (5%). However, as indicated in Table 3, not all respondents knew their HIV status (10% of new patients, 20% of retreatment patients, and 25% of MDR-TB patients were unaware of their status). About 37% of HIV-positive patients received services in the largest cities (Santiago and Santo Domingo), and about 34% of respondents from these areas did not know their HIV status, which is higher than the reported average.

**TABLE 6. Total median costs (direct and indirect) incurred by tuberculosis (TB) patients (*n* = 198) by type of patient (new, retreatment, and MDR-TB[a]), Dominican Republic, 2009**

| Costs | Type of patient | | |
|---|---|---|---|
| | New | Retreatment (in US$[b]) | MDR-TB |
| Direct | | | |
| Before and during diagnosis | 45.5 (26%) | 112.7 (54%) | 154.1 (37%) |
| Treatment | 134.9 (74%) | 98.1 (46%) | 257.9 (63%) |
| Subtotal direct | 180.4 (20%) | 210.8 (49%) | 412.0 (12%) |
| Indirect | 726.4 (80%) | 220.8 (51%) | 3 145.0 (88%) |
| Total | 906.8 | 431.6 | 3 557.0 |

[a] MDR-TB: multidrug-resistant tuberculosis.
[b] US$1 = RD$ 36.06 (2009).

**FIGURE 2. Individual median monthly income[a] among tuberculosis (TB) patients before and after onset of TB by income group, Dominican Republic, 2009[b]**




[a] In US$ (US$1 = RD$36.06 [2009]).
[b] Income categories: very low, < $42/month; low, $42–$83/month; medium, $84–$166/month; higher, $166/month.

## Insurance

Approximately one-third of respondents were covered by health insurance during the time of the study. Of these, 62% obtained private insurance and 32% were part of the national health insurance scheme. Two respondents received a median insurance reimbursement of US$ 1 000 for expenditures related to TB. The other 196 respondents did not receive any reimbursements. Most health insurance schemes in the DR do not cover TB-associated health care costs.

# DISCUSSION

## Key findings

Findings of this study suggest that TB patients in the Dominican Republic face a severe financial burden as a result of falling ill with the disease. Information on the education level of the study population (Table 3) suggests that this affects the most vulnerable of society. Due to TB, direct and indirect costs increased while income decreased for the majority of patients. The proportion of patients without a regular income increased from 1% to 54% because of TB. Retreatment and MDR-TB patients are comparably worse off than new patients because of the severity of illness and related inability to work, costly tests and medicines, and longevity of treatment. Patients attending private clinics spent more than patients attending public sector sites. HIV-infected TB patients were disadvantaged by a lack of TB/HIV integrated services necessitating additional trips to health facilities. Guardians fulfill an important role in assisting patients during their appointments at the health facility and as treatment observers. The fact that almost half of all interviewed patients incurred debt and 65% of patients mentioned food coupons as a means to alleviate their situation underlines the severe impact TB has on the welfare of the household. This situation was exacerbated for those who were hospitalized and therefore incurred higher direct and indirect costs. The high costs of hospitalization and the length of stay could be related to delays in seeking care (5–6 weeks) and therefore late diagnosis and advanced stage of the disease. Women incurred comparatively higher hospitalization costs than men, but it is not clear whether women were actually charged higher costs or estimated higher costs when interviewed. The information collected on health-seeking behavior and HIV status, and the high proportion of direct costs for new patients for diagnostic tests (22%) and medications (36%) unrelated to TB (particularly in private clinics), suggests a lack of knowledge of HIV and TB among the general population.

## Policy recommendations

Given the findings on the costs of hospitalization and HIV-related and diagnostic tests, in consultation with the Ministry of Health, the recommendation was made to improve the quality of care for TB patients in the private and public primary care sectors. Furthermore, given the high hospitalization costs, decentralization of TB services at the primary care level was recommended to reduce the involvement of hospitals and shorten paths to diagnosis and treatment. The lack of knowledge on TB and HIV prompted the recommendation to strengthen awareness-raising on TB and HIV among health care workers and the general population to reduce delays in diagnosis. The severe impact of TB-related costs on the welfare of the household led to the recommendations to advocate for the inclusion of TB services in national health insurance schemes and to consider food and transport subsidies, especially for retreatment and MDR-TB patients. For better social and workplace reintegration of TB patients, collaboration with other government institutions such as the Solidarity Program (*Programa de Solidaridad*); the "Eating Comes First" ("*Comer Es Primero*") program; and the National Institute of Technical and Vo-

cational Training (*Instituto de Formación Técnico Profesional*, INFOTEP) was also recommended.

The Ministry of Health looked into the findings of this study in depth and explored the possibilities for implementing the recommendations. In 2011 it decided to move forward with allocating public funds for food supplements for TB patients and including in- and outpatient TB services in the national health insurance schemes.

## Study limitations

This study had some limitations. First, as areas with a high TB burden were purposively sampled, and TB is closely linked to poverty (1, 2), the purposive sampling method may have led to an over-representation of low-income populations. Second, questions about costs and income are subject to recall bias and seasonal fluctuation (18). This is particularly true for retreatment and MDR-TB patients, who often experience several health care–seeking episodes between onset of symptoms and diagnosis of drug-resistant TB. Including retreatment and MDR-TB patients in the study was nevertheless a deliberate choice of the study team, and was requested by the Ministry of Health, as these groups of patients have severe forms of the disease and require long-term treatment and are thus considered the most vulnerable. Third, estimating costs and incomes in monetary terms is difficult, particularly when distinguishing between income and turnover. Comparing the 2009 income data with 2004 UNDP income data (14) reveals that half of the interviewees earned more per month (> US$ 166) before they became ill than the average population in 2004 (US$ 170.5; US$1 = RD$ 28.4). This could be attributed to overestimation in this study, or it could be due to increasing wages, economic growth, and inflation during that period. After onset of TB, however, the picture changes dramatically. The majority of TB patients earned less than US$ 42 per month, which is significantly less than the US$ 170.5 reported by the UNDP.

The contribution of external income sources from relatives or friends was not explicitly asked during interviews. Premiums paid for health insurance were not deducted when calculating expenditures. As only two patients received significant reimbursements, however, this omission should not have had a large effect on results. Differences between the study areas were considered beyond the purpose of this study and thus were not determined by means of sensitivity testing.

Patient cost studies done in other parts of the world show similar findings (5–8, 18–21). Although numbers cannot be directly compared due to the different methodologies employed, similar patterns are visible: indirect costs are higher than direct costs and total costs are beyond 10% of annual income. These patterns indicate the need for the state to protect its population from the economic and health effects of contracting TB and to prevent an increase or deepening of poverty among those suffering from the disease. This finding also exemplifies the need to further investigate and limit costs incurred by MDR-TB patients.

## Conclusions

Findings of this study confirm a pattern shown by other TB patient cost studies in the world: TB patients in the DR face a great financial burden without the necessary social protection. Free TB diagnosis and treatment are not enough to alleviate the vulnerable from financial constraints due to the illness. Health insurance covering TB in- and outpatient costs and integrated TB/HIV services are crucial to prevent TB-related financial hardship.

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**RESUMEN**

## Los pacientes con tuberculosis en la República Dominicana afrontan altos costos directos e indirectos, y necesitan protección social

***Objetivo.*** Examinar los costos directos e indirectos afrontados por los pacientes con tuberculosis en la República Dominicana, ya sea por un tratamiento nuevo, por retratamiento, o por una tuberculosis multirresistente (MR), antes y a lo largo del proceso diagnóstico y durante el tratamiento, con objeto de generar una base de datos probatorios y formular recomendaciones.

***Métodos.*** El "Instrumento de cálculo de los costos afrontados por los pacientes" ("Tool to Estimate Patients' Costs") se adaptó al entorno local, se tradujo al español y se sometió a una prueba preliminar. Durante los días en que se llevó a cabo el estudio, se entrevistó a los pacientes que acudían a 32 establecimientos de salud seleccionados aleatoriamente en seis zonas elegidas para ello. Se recopilaron las respuestas de los pacientes de 18 a 65 años de edad que habían recibido tratamiento durante al menos un mes y que habían prestado su consentimiento por escrito. Las respuestas se introdujeron en una base de datos y se analizaron.

***Resultados.*** Se entrevistó a 200 pacientes. Para la mayoría de los entrevistados, los costos directos e indirectos aumentaban a medida que se reducían sus ingresos. Los costos totales ascendieron a una mediana de US$ 908 para los nuevos pacientes, US$ 432 para los pacientes en retratamiento y US$ 3 557 para los pacientes con tuberculosis multirresistente. La proporción de pacientes sin ingresos regulares aumentó de 1 a 54% como consecuencia de haber contraído la tuberculosis. Después de examinar los resultados del estudio, el Ministerio de Salud ha llevado a cabo iniciativas con objeto de asignar fondos públicos para suplementos alimentarios y para incluir los servicios de atención hospitalaria y ambulatoria de la tuberculosis en los programas del seguro nacional de enfermedad.

***Conclusiones.*** El diagnóstico y el tratamiento gratuitos de la tuberculosis no son suficientes para mitigar las limitaciones financieras afrontadas por los grupos vulnerables como consecuencia de la enfermedad. Es esencial que el seguro de enfermedad cubra los costos de la atención hospitalaria y ambulatoria de la tuberculosis para paliar las dificultades financieras relacionadas con la enfermedad.

**Palabras clave** Tuberculosis; tuberculosis resistente a múltiples medicamentos; costo de enfermedad; República Dominicana.