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Households of tuberculosis (TB) patients face high TB-related costs in Somalia

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Abstract

Background The out-of-pocket spending and costs incurred by households affected by tuberculosis (TB) while accessing TB services in Somalia remain unclear. This study is the first of its kind in Somalia, estimating the proportion of TB-affected households that experience catastrophic costs among individuals with TB.

Methods A nationally representative, descriptive, cluster-sampled cross-sectional survey was conducted among individuals receiving TB care within the Somali National TB network from December 28, 2023, to February 3, 2024. It utilized retrospective data collection to gather information on participants' sociodemographic and clinical characteristics, including care models, self-reported income and expenses, and the costs (out-of-pocket expenses and indirect) associated with a single episode of TB. The survey also examined risk factors for incurring these costs and mechanisms for dissaving. TB catastrophic cost is defined as the total costs (both direct and indirect) incurred during TB illness and treatment that exceed 20% of a household's annual income.

Results Overall, 68% (95% CI: 64%–71%) of households affected by TB in Somalia faced costs exceeding 20% of their household income. Among patients receiving first- and second-line drug treatment, the percentages were 69% (95% CI: 65%–73%) and 62% (95% CI: 52%–71%), respectively. Individuals with TB living in the Southwest states were the most likely to incur catastrophic costs associated with the disease. Self-reported monthly household income decreased by 43%, dropping from US \$176 before contracting TB to US \$101 during the interview. A total of 75.4% (364) of households facing TB-related catastrophic costs reported a decline in their financial situation while seeking TB services. To cope with the economic burden of TB-related catastrophic expenses, 42% (375) of individuals with TB and their households relied on one or more dis-saving strategies, such as taking out loans or selling assets.

Conclusions This study found that almost three out of four patients in TB care and their households experience a substantive economic burden accessing TB services in Somalia, particularly during the continuation phase of their treatment, and mainly driven by the direct nonmedical costs. A sustainable and equitable social protection program is required to reduce the proportion of households facing economic burdens due to TB in Somalia.

Keywords Tuberculosis, Catastrophic total costs, Somalia, Out-of-pocket costs, Total costs for TB, Out-of-pocket spending

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Background

TB remains a significant threat to human health, ranking as the second leading cause of death from a single infectious disease after COVID-19 and causing double the fatalities recorded for HIV/AIDS in 2022 [1–4]. Globally, in 2022, an estimated 10.6 million and 1.3 million individuals developed TB and died from the disease, respectively, while 50% of TB patients and their households face total costs that are >20% of their annual household income [2]. These figures are far from the WHO End TB Strategy target of reducing TB incidence and deaths by 50% and 75%, respectively, and TB-related catastrophic costs to 0% by 2025. High out-of-pocket expenses and lost income before and during TB diagnosis or treatment are significant factors limiting TB control efforts in many countries, thereby hindering progress toward achieving the WHO End TB Strategy 2025 milestones [5–7].

The TB situation in Somalia is complicated by a high incidence rate of 246 and a mortality rate (excluding TB/HIV deaths) of 63 per 100,000 people per year in 2022. The country ranks among those with the highest burdens of rifampicin-resistant/multidrug-resistant TB (RR/MDR-TB), reporting 18,458 incident TB cases (all forms) out of an estimated 43,000 incident cases in 2022 [2, 8]. The tuberculosis program relies heavily on donor support and operates in a challenging environment [9, 10]. TB services (diagnosis, treatment, care, and prevention) are provided free of charge and are made accessible throughout the country. However, TB-affected households still face substantial indirect costs associated with accessing TB care and services, impacting the overall care cascade and ultimately leading to poor treatment outcomes and an increased risk of TB transmission [11–13]. In many cases, the costs of obtaining TB care are hidden as out-of-pocket expenses, both medical and non-medical, particularly in low- and middle-income countries [14]. This situation is likely similar in Somalia.

Social protection and health insurance, which present a promising pathway to achieving universal health coverage, remain scarce in Somalia [8, 9]. Health insurance coverage is low, as only 2% of households utilize insurance for their health expenses; for example, 99.9% of women aged 15–49 who have ever married, regardless of their age, type of residence, education, or wealth quintile, lack any form of insurance [10]. Also, direct benefits to prevent poverty are generally unavailable due to a weak social protection framework, thereby encouraging out-of-pocket expenditure [8, 10]. Through funding from the Global Fund and Médecins Sans Frontières (MSF), individuals on second-line TB treatment and care are supported with cash to cover their travel and food expenses, including directly paying for their baseline and treatment monitoring tests. This support is limited, indicating that

the overall social support packages and social protection interventions available to individuals with TB in Somalia are inadequate [11].

Currently, the costs incurred by patients accessing TB services in Somalia remain largely unknown, as highlighted by the global WHO monitoring [1, 2, 12]. As part of Somalia's 3-Year National TB Strategic Plan to reduce TB-related catastrophic costs [13], this first national survey of costs faced by households affected by tuberculosis aims to estimate the proportion of TB-related catastrophic costs among individuals receiving TB care (and their households) and to evaluate the association between these costs and significant risk factors (age, sex, education, occupation, drug susceptibility, state of residence, HIV status, and household size) within this population. For sampling purposes, we hypothesize that fewer than 50% of individuals with TB and their households experience TB-related catastrophic costs, with similar costs per episode borne by patients on first-line and second-line treatment.

Methods

Study design

This study, a nationally representative descriptive cluster-sampled cross-sectional survey using retrospective data collection, was conducted across seven states in Somalia from December 28, 2023, to February 3, 2024, to determine TB catastrophic cost (the percentage of TB-affected households incurring out-of-pocket costs exceeding 20% of the household's annual income) and the “dissaving” (such as loans taken, property or livestock sales in Somalia) [14]. It was designed based on the World Health Organization's Handbook guidance on National TB Patient Cost Surveys [14]. This guidance also shaped the development of objectives, the data collection plan, management, and other aspects of the study methodology, including data cleaning and analysis. Contextual questions about facility categories, depending on the type of support received, were included. The study site consisted of 96 public and private TB Management Units (TBMUs) within the National TB Program (NTP) network that treated and reported TB cases according to the national TB program's guidelines in 2022.

Study setting

Somalia is Africa's easternmost country in the continent's Horn, covering an area of 637,657 sq. km, bordered west by Ethiopia, north by the Gulf of Aden, east by the Somali Sea and Guardafui Channel, and southwest by Kenya [10]. Administratively, it comprised seven states, Galmudug, Hirshabelle, Benadir, Jubbaland, Southwest, Puntland, and Somaliland, and has a 2023 projected population of about 18,143,378

million based on a 3.1% annual growth rate with 51% living in urban areas, 23% in rural, and 26% in nomadic area [10, 15]. Despite the protracted period of political instability, Somalia's economy has made appreciable progress but remains among Africa's poorest and least developed countries, with an estimated gross domestic product (GDP) of US \$10.4 million and a GDP per capita of approximately US \$592 in 2022 [16].

Somalia's healthcare delivery system is diverse and cuts across all levels of governance, involving multiple layers from the public and private sectors, including the community [17]. The government focused on scaling up essential and fundamental health and nutrition services through the Essential Package of Health Services, developed in 2009, and overcoming the crisis of human resources for health, among others [8, 9, 18]. TB services are delivered through 111 TB Management Units (TBMUs), three drug-resistant TB (DR-TB) hospitals, three National TB Reference Laboratories (NTRLs), and the community. Every TBMU provides laboratory services, and the three NTRLs support the laboratory network in the country under the supervision of the supranational laboratory in Uganda. DR-TB services are decentralized and integrated into the TBMUs nationwide. Though the private sector provides the bulk of health services in Somalia through private hospitals and clinics and plays an essential role in TB control, management, and service delivery, their involvement in delivering TB services is still limited [19, 20]. Also in existence is a robust community structure for TB service delivery through the support of the community and female health workers who deliver TB services.

Study population

The study population includes all patients (males, females, and children accompanied by a guardian) diagnosed and registered for TB treatment within Somalia's NTP network who visit a sampled facility during the study period. This comprises all patients on first-line (DS-TB) and second-line (DR-TB) drug treatment who have been on TB treatment for at least 2 weeks (14 days), whether in the continuation or intensive phase. Since this survey relies heavily on self-reported data, it excludes individuals with language, auditory, and cognitive impairments, children without a guardian who cannot provide adequate and reliable information, and those not currently receiving TB treatment. Furthermore, given the current Somali context, patients receiving treatment from health facilities in security-challenged districts were excluded.

Procedures

Sampling

This study employed a random cluster-based sampling method and the probability proportional to size sampling technique to determine the sample size and select the appropriate clusters. A TB treatment facility (public and private hospitals, clinics, and health centers) called TBMU represented a cluster in the survey's primary sampling unit. In contrast, the individuals receiving treatment in these clusters were considered the secondary sampling unit and the unit of analysis.

All the 111 TBMUs (clusters) across the seven states with their corresponding reported 2022 TB cases, totaling 18,499, were listed as the sampling frame. Then, TBMUs that did not report any TB cases in 2022 and those that were inaccessible due to insecurity were removed from the sampling frame; these amounted to 15 TBMUs, leaving a total of 96 TBMUs to serve as the survey's sampling frame. The remaining 96 TBMUs were randomly sorted using a computer-generated command and other computations to determine the required 37 clusters.

Three consecutive steps guided the calculation of the sample size. These included calculating the initial sample size, determining the design effect (Deff), and then calculating the required minimum sample size for the study, considering this is a cluster-type survey design. The Deff is the adjustment made to estimate how much the expected sampling error deviates from the sampling error that would occur if a simple random sampling method were used and to find the desired minimum sample size [19]. It is estimated using the intra-cluster correlation and the number of individuals in each cluster (m). A formatted Excel template was used to calculate the minimum sample size of 878, which was later adjusted upward to 927 to accommodate nonresponses at 5.2%. The output provided an estimated sample size of 927 patients, corresponding to 37 clusters with 25 patients per cluster. These steps are summarized by the formula below:

$$n = D * \frac{p(1-p)z^2}{d^2}$$

n = Minimum sample size.

D = Is the design effect (Deff) if cluster sampling was used: $1 + I(m - 1) = (1.12)$.

I = Intra-cluster correlation (0.005).

m = Number of individuals in each cluster (25).

p = Is the anticipated population proportion (50%).

d = Is the precision required on either side of the proportion (0.035).

z = Is the cut-off value of the normal distribution (1.96).

The exact proportion of households in Somalia reporting catastrophic health spending could not be established. Therefore, 50% was used to hypothesize the proportion (p) of households experiencing catastrophic total costs due to TB disease in Somalia. This aligns with the Somali 2020 Health and Demographic Survey report that indicates 98% of households pay for their health expenses through their income (48%), the selling of assets (11%), borrowing money (14%), and support from friends and relatives (25%) [17].

Survey and data collection

The survey organization comprises a core team of eight technical experts (NTP, WHO country office, World Vision, external technical assistance from the WHO), a data manager, a coordinator, and a local survey team to plan, design, and implement the survey. The local survey team comprises 36 interviewers/data collectors (one per cluster) and 7 state TB coordinators (one per state) who collected the survey data. The interviewers were trained virtually due to inadequate resources and given Android phones to collect and upload interview information. The training lasted for 3 days, and each participant's understanding of the tool was tested through a practical session where they were asked to enter hypothetical information.

The instrument utilized for data collection in this survey is a structured, standardized questionnaire adapted from the WHO's generic patient cost survey instrument for collecting data from individuals with TB [14]. It comprises 5 sections totaling 115 questions: (i) informed consent and inclusion/exclusion criteria for all eligible patients; (ii) patient information gathered from the TB treatment card prior to the interview for all eligible patients; (iii) an overview of TB treatments prior to the current regimen, covering up to 5 years before the current treatment began, applicable only to retreatment cases and administered during the intensive phase; (iv) costs incurred before the current TB treatment for new cases interviewed exclusively during the intensive phase; and (v) costs associated with the current DS-TB/DR-TB treatment, administered to all eligible patients.

The data collection instrument included questions on socioeconomic position, household composition, employment status, healthcare utilization, hospital visits, time spent and income lost while seeking and receiving care, household assets, costs incurred (direct medical, direct non-medical, and indirect), individual and household income, access to social protection, coping strategies (loans taken and assets sold), and social consequences, including perceived impacts of costs to make up the required number (25) per cluster. An electronic data collection tool was programmed and deployed into the Kobo Toolbox (KoboCollect). The

e-survey tool contains skip patterns, which enable respondents to be directed to different sections of the survey according to their type of TB and whether they were interviewed during the intensive or continuation phase for ease of operation.

The survey implementation, which started with a pilot phase, lasted about 6 weeks between 28 December 2023 and 3 February 2024. The pilot exercise enabled the team to identify potential challenges using the tool and assisted in validating assumptions made for sample size calculation, mode, timing of interview, and budget. Ten trained interviewers were deployed over 2 weeks to conduct the pilot testing in 10 non-survey selected clusters, and the findings from the pilot exercise were used to improve the wording of the questionnaire sequence, structure, and overall survey implementation plan.

Eligible participants were enrolled in the study through random selection from the facility treatment register. Data variables such as demographic and clinical parameters (age, type of TB patient, HIV status, and treatment duration) were extracted from the facility treatment registers and cards before the interview. While ensuring optimum confidentiality, trained interviewers collected data face to face over 1 h. In facilities with high patient turnout during clinic visits, particularly for drug-susceptible TB, consecutive eligible patients were interviewed as they visited the clinic until the sample size was completed. In contrast, in low-volume facilities, they were randomly selected from the register and mobilized to the facilities for the interview. To ensure adequate representation of DR people with TB, all participants who were with DR-TB were selected as they showed up.

Statistical analysis

Data processing

Data cleaning and analysis were performed using R statistical software, version 4.3.1 [21]. This process involved separating and linking patient-level repeat records, such as pre-diagnostic visits and hospitalization information, to the primary patient record through unique patient identifiers. The WHO R script was adapted for Somalia's instrument design, allowing for range and format checks on various variable types, particularly for cost and time variables [22]. Additionally, consistency checks were conducted across questionnaire sections, which included formatting variable names and labels. The cleaned data were analyzed based on the survey objectives [21]. Missing data were identified and point imputed, particularly regarding cost extrapolations for patients receiving first-line and second-line treatment throughout the expected treatment period, following WHO guidance on analyzing TB cost survey data.

Analysis process

The analysis started with basic descriptive statistics and cross-tabulations describing some selected participants' socio-demographics, treatment characteristics, and the country's TB care model. The analysis process summarized categorical variables using absolute frequencies (proportions) and continuous variables using medians, interquartile ranges (IQR), means, standard deviations (SD), and 95% confidence intervals (95% CI) stratified by drug sensitivity status (DS-TB or DR-TB) and gender (female or male). The total costs incurred during TB treatment, the estimated hours participants lost seeking care, and the delays experienced in seeking care were calculated. Also, the analysis computed the proportion of TB-affected households experiencing catastrophic costs and the proportion of households experiencing "dissaving," including assessing the cost drivers for seeking TB care, coping strategies employed, and the social consequences faced for contracting TB in Somalia. All cost and income data were collected and computed in United States dollars (USD).

Estimation of the costs of a TB episode

The analysis assessed self-reported income for participants (individuals) and their households, estimated the cost of a TB episode, and valued the time each participant spent seeking TB diagnosis, treatment, and care; assessed income by asking participants about their individual and household income before and after TB diagnosis. The estimated costs of a TB episode were calculated as the total costs (direct medical, direct non-medical, and indirect) per TB episode, starting from the onset of symptoms to TB treatment completion. The direct medical costs include costs reported for day charges for hospital admissions, consultation, radiography and other imaging, laboratory tests, other procedures, TB medicine, other medicine, and other medical costs. The direct nonmedical costs included all travel costs, food during healthcare visits or hospital stays, nutritional supplements during healthcare visits or hospital stays, and other nonmedical expenses (including accommodation and food). For this study, the indirect cost was viewed as the productivity and economic costs incurred by the survey participants or their households due to TB healthcare visits and hospitalization during TB episodes and calculated using the output approach (self-reported household income before TB minus self-reported household income during TB treatment or at the time of interview) [14, 23].

Estimation of catastrophic costs and dissaving

Furthermore, following WHO global monitoring, the percentage of individuals in TB care and their households that experienced catastrophic total costs was defined and

calculated as exceeding 20% of annual household income. After that, it was determined whether the participants and their households incurred catastrophic costs due to TB at this threshold by assigning them a binary number [24]. Then, the proportion of those who incurred catastrophic costs due to TB illness was calculated as a percentage and reported as the proportion of TB-affected households experiencing catastrophic costs. In addition, the coping strategies used (defined as whether the participant or their household received loans or sold their assets) were analyzed as binary measures to determine whether participants or their households adopted any coping strategy. The dissaving strategies in the form of loans (borrowed money) or sales of assets were calculated.

Factors associated with TB costs

Lastly, logistic regression was used to identify the risk factors related to TB-related costs experienced by patients receiving TB care and their households through both univariable and multivariable analyses. The results were presented as odds ratios, 95% confidence intervals, and the corresponding *p*-values.

Results

Participant characteristics

Out of the 927 eligible patients recruited for the study, 901 (97.2%) consented to participate and were interviewed, with 710 (78.8%) providing complete cost records. The sociodemographic and clinical characteristics of the study population are detailed in Table 1. The median age was 32 years [interquartile range (IQR) 22–48], with 78 (8.6%) of participants being under the age of 15. A greater number of male respondents participated, with 565 (62.7%) versus 336 female respondents (37.3%). Among those surveyed, 764 (84.8%) were receiving first-line TB treatment, while 137 (15.2%) were undergoing second-line TB treatment. Furthermore, 507 (56.3%) were in the continuation phase at the time of the interview, and 24 (2.7%) had a history of previous TB treatment. Of the 808 (89.7%) who were aware of their HIV status, 7 (0.8%) were living with HIV. Nearly all participants, 99.9% (900), lacked health insurance or any safety net to help offset the cost of TB treatment services. Additional sociodemographic and clinical parameters are presented in Table 1.

TB model of care

Table 2 displays key variables in the care model reported in the survey. Overall, 214 respondents (23.8%) indicated that they had experienced at least one hospitalization during their current treatment phase. This group includes 5.4% who were previously admitted and 18.3%

Table 1 Characteristics of survey participants (Somalia, 2024)[Aikira1] [Aikira1]CE: This is unidentified paragraph from coast

	Patients on first line TB treatment		Patients on second line TB treatment		All Patients on TB treatment	
	N	%	N	%	N	%
Total	764	100.0	137	100.0	901	100.0
Demographic characteristics						
Sex						
Female	295	38.6	41	29.9	336	37.3
Male	469	61.4	96	70.1	565	62.7
Age, Median (Q1, Q3)	32 (21, 48)		33 (25, 45)		32 (22, 48)	
Age range (years)						
<15	72	9.0	6	4.4	78	8.6
15-49	517	68.0	106	77.4	623	69.2
50+	175	23.0	25	18.2	200	22.2
Education level						
No education	472	61.8	85	62.0	557	61.8
Primary-Secondary	269	35.2	49	35.8	318	35.3
University	23	3.0	3	2.2	26	2.9
Occupation						
Unemployed	504	66.0	100	73.0	604	67.0
Employed	260	34.0	37	27.0	297	33.0
Insurance status						
No insurance	763	99.9	137	100.0	900	99.9
Insurance	1	0.1	0	0.0	1	0.1
Household size, Median (Q1, Q3)	5 (3, 8)		6 (0, 8)		5 (3, 8)	
Category of facility						
Private	48	6.3	0	0.0	48	5.3
Public	716	93.7	137	100.0	853	94.7
Clinical characteristics						
Treatment Phase						
Intensive phase	292	38.2	102	74.5	394	43.7
Continuation phase	472	61.8	35	25.5	507	56.3
Treatment category						
New	757	99.1	120	87.6	877	97.3
Retreatment	7	0.9	17	12.4	24	2.7
HIV Status						
HIV negative	679	88.9	122	89.1	801	88.9
HIV positive	6	0.8	1	0.7	7	0.8
Unknown	79	10.3	14	10.3	93	10.3
Treatment support						
Self-administered	559	73.2	102	74.5	661	73.4
Directly observed therapy	205	26.8	35	25.5	240	26.6

who are currently admitted, with a median hospitalization duration of 43 days (*IQR*: 7, 67). This highlights the critical role of hospital admissions in the Somalia TB care model. Additionally, the median number of visits before

TB diagnosis and TB-related follow-up visits during the current treatment phase were both 1 (*IQR*: 1, 1) and 1 (*IQR*: 1, 3), respectively. The median number of weeks before starting TB treatment after diagnosis was 2 (*IQR*:

Table 2 Key model of care variables for TB (hospitalization, treatment duration, and delay) (Somalia, 2024)

Variable	DS-TB*	DR-TB**	All***
Model of care (Hospitalization), N (%)	N = 764	N = 137	N = 901
Hospital admission during current treatment phase (total)	133 (17.4)	81 (59.1)	214 (23.8)
Hospital admission during current treatment phase (at interview)	104 (13.6)	61 (44.5)	165 (18.3)
Hospital admission during current treatment phase (before interview)	29 (3.8)	20 (14.6)	49 (5.4)
Model of care (Ambulatory), Median (Q1, Q3)	N = 764	N = 137	N = 901
Number of visits before TB diagnosis	1 (1, 1)	1 (1, 1)	1 (1, 1)
Number of TB-related follow-up visits during current treatment phase	1 (1, 2)	2 (1, 4)	1 (1, 3)
Number of Directly observed therapy (DOT) visit per week	6 (3, 7)	7 (7, 7)	6 (5, 7)
Model of care (Time lost pre-diagnosis), Median (Q1, Q3)	N = 363	N = 109	N = 472
Travel time to hospital pre-diagnosis (minutes)	60 (25, 100)	60 (30, 60)	60 (29, 90)
Model of care (Time lost post-diagnosis), Median (Q1, Q3)	N = 124	N = 67	N = 191
Travel time to hospital for TB care (minutes)	30 (0, 55)	30 (20, 60)	30 (15, 60)
Number of days on hospital admission	43 (7, 60)	56 (6, 180)	43 (7, 67)
Treatment delay, Median (Q1, Q3)	N = 369	N = 67	N = 436
Number of weeks before start of TB treatment following diagnosis	2 (1, 7)	3 (1, 10)	2 (1, 7)
Number of weeks before start of TB treatment after first symptom	2 (1, 4)	3 (2, 4)	3 (1, 4)

*Patients on first line TB treatment; **Patients on second line TB treatment; ***All patients on TB treatment

*Patients on first line TB treatment, **Patients on second line TB treatment, ***All patients on TB treatment, ^Indirect costs, measured using output approach

Table 3 Cost incurred by patients in TB care and their households by phase of treatment and cost type (Somalia, 2024)

Variable	DS-TB*		DR-TB**		All***	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
Total costs	363	236 (72 - 621)	109	115 (55 - 305)	472	154 (70 - 560)
Cost category (Cost type)						
Direct medical costs	363	50 (25 - 103)	109	42 (0 - 112)	472	50 (15 - 108)
Direct nonmedical costs	363	85 (33 - 295)	109	61 (19 - 160)	472	78 (29 - 223)
Indirect costs^	363	0 (0 - 50)	109	0 (0 - 33)	472	0 (0 - 50)
Cost category (Phase)						
Pre-diagnosis	363	44 (11 - 115)	109	72 (25 - 119)	472	50 (12 - 115)
Direct medical costs	363	25 (0, 55)	109	48 (0, 68)	472	26 (0, 62)
Direct nonmedical costs	363	5 (0, 10)	109	6 (4, 18)	472	5 (0, 12)
Post-diagnosis (int. phase)	84	31 (4 - 180)	32	18 (0 - 93)	116	30 (1 - 117)
Direct medical costs	84	40 (25, 72)	32	42 (0, 80)	116	41 (15, 75)
Direct nonmedical costs	84	68 (21, 263)	32	60 (21, 129)	116	62 (21, 201)
Indirect costs^	84	0 (0, 58)	32	0 (0, 3)	116	0 (0, 38)
Post-diagnosis (cont. phase)	43	115 (68 - 330)	21	37 (8 - 358)	64	110 (47 - 348)
Direct medical costs	43	75 (36, 163)	21	68 (0, 195)	64	74 (25, 173)
Direct nonmedical costs	43	131 (49, 333)	21	99 (15, 170)	64	120 (45, 279)
Indirect costs^	43	0 (0, 243)	21	0 (0, 0)	64	0 (0, 125)

*Patients on first line TB treatment; **Patients on second line TB treatment; ***All patients on TB treatment

^Indirect costs, measured using output approach

*Patients on first line TB treatment, **Patients on second line TB treatment, ***All patients on TB treatment, ^Indirect costs, measured using output approach

1, 7) and 3 (IQR: 1, 4) weeks following the onset of the participant's first TB symptoms (Table 2).

Costs incurred by patients in TB care

According to Table 3, the median cost for a TB episode in Somalia was US \$154 (IQR: 70–560). The direct non-medical costs had the highest median at US \$78 (IQR: 29–223), followed by direct medical costs at US \$50 (IQR: 15–108), while indirect costs had the lowest median at US \$0 (IQR: 0–50). Overall, the median cost for DS-TB is US \$236 (IQR: 72–621), which is double that of DR-TB at US \$115 (IQR: 55–305). The post-diagnostic costs, especially during the continuation phase, showed that direct nonmedical expenses (US \$120 [IQR: 45–279]) had the highest median compared to any other category in the pre-diagnostic or intensive phases of treatment. During the intensive phase, the median direct nonmedical cost was US \$62 (IQR: 21–201), slightly higher than the direct medical cost of US \$41 (IQR: 15–75). Before diagnosis, the median direct medical cost was US \$26 (IQR: 0–62), which was greater than the nonmedical cost of US \$5 (IQR: 0–12), consistent for both DS-TB and DR-TB. In summary, the median cost of accessing TB treatment was noticeably higher among people with DS-TB during the post-diagnostic phase compared to those with DR-TB, but it was lower in the pre-diagnostic phase (US \$44 [IQR: 11–115] vs. US \$72 [IQR: 25–119]).

Changes in household income

Table 4 outlines the changes in household income related to TB and illustrates how both contracting and treating TB affect household finances. On average, the estimated monthly household net income from labor-related activities before contracting TB was US \$142 (95% CI: 83–201). This amount declined to US \$115 (95% CI: 74–156) at the time of diagnosis and further decreased to US \$88 (95% CI: 59–117) during the interview. To access TB treatment and care services and manage the financial implications of TB, 42% (379) of patients receiving TB care and their households employed one or more dis-saving

strategies, such as taking out loans or selling assets (see Table 5). The catastrophic costs associated with TB have significantly affected the social lives and economic situations of patients receiving TB care in Somalia. Among the total survey respondents, 379 (42%) reported that accessing TB services greatly influenced their social lives and finances, including their overall well-being. This effect was notably severe among patients diagnosed with DS-TB (46%) compared to those with DR-TB (15%). Additionally, 71% (640) of the households of survey participants indicated being in a worse economic position, with 23% (145) experiencing a significant decline in wealth; this trend was especially noticeable among individuals diagnosed with DS-TB.

TB-related catastrophic costs

The proportion of patients receiving TB care and their households facing TB-related catastrophic costs was 68% (95% CI: 64%–71%). This rate was slightly higher among individuals with DS-TB (69% [95% CI: 65%–73%]) compared to those with DR-TB (62% [95% CI: 52%–71%]) at the 20% threshold (Fig. 1). The proportion of people with TB and their households experiencing TB-related catastrophic costs was assessed at different cut-off points through sensitivity analysis. This analysis revealed that the proportion increased to 73% at a 10% threshold and decreased to 58% at 40% (Fig. 1).

The multivariable analysis examining the risk factors associated with catastrophic costs among TB care patients assessed crude and adjusted odds ratios, confidence intervals, and statistical significance across study variables with a 20% cutoff (Table 6). The Southwest state showed significantly higher catastrophic costs than the Banaadir state (adjusted OR 0.15, 95% CI: 0.03–0.72). No significant differences were observed in TB-related catastrophic costs across age groups, gender (male and female), employment status (unemployed and employed), recorded HIV status (negative, positive, and unknown), type of health facility (private and public), TB sensitivity (DS-TB and DR-TB), household size, social impact (yes

Table 4 Changes in household income due to TB (Somalia, 2024)

Variables [‡]	DS-TB* [‡]	DR-TB** [‡]	All*** [‡]
	N = 384	N = 117	N = 501
Household estimated net income from, Mean (95% CI):			
Labor-related activities/month before contracting tb [‡]	157.3 (88.7 - 225.9) [‡]	90.2 (51.8 - 128.6) [‡]	141.9 (82.9 - 200.9) [‡]
Labor-related activities per month at the time of diagnosis	120.5 (74.0 - 167.0) [‡]	95.4 (47.0 - 143.8) [‡]	114.7 (73.9 - 155.5) [‡]
Labor-related activities per month at the time of interview	92.3 (59.2 - 125.4) [‡]	73.1 (45.3 - 100.9) [‡]	87.8 (58.6 - 117.0) [‡]

*Patients on first line TB treatment; **Patients on second line TB treatment; ***All patients on TB treatment[‡]

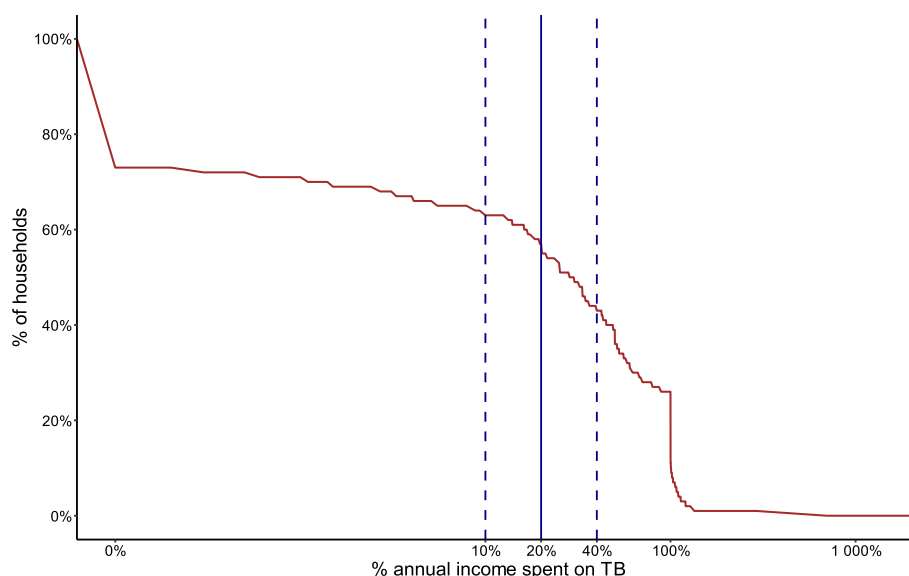
[‡]Patients on first line TB treatment, ^{**}Patients on second line TB treatment, ^{***}All patients on TB treatment

Table 5 Coping strategies and impact of catastrophic costs on the social life and finance of people with TB (Somalia, 2024)

	TB Sensitivity		Sex		All
	DS-TB* N = 764	DR-TB** N = 137	Female N = 336	Male N = 565	All*** N = 901
Dissaving (Coping strategy), % (95% CI)					
Loan	30 (27 - 33)	2.9 (0.9 - 7.8)	26 (22 - 32)	25 (22 - 29)	26 (23 - 29)
Sale of assets	18 (16 - 21)	1.5 (0.3 - 5.7)	18 (14 - 22)	15 (12 - 18)	16 (14 - 18)
Dissaving Amount, Mean (95% CI)					
Loan	420 (354 - 487)	165 (85) (30, 300)	318 (225 - 412)	475 (387 - 563)	416 (351 - 482)
Sale of assets	553 (370 - 736)	1,275 (-14,290 - 16,840)	389 (240 - 538)	692 (395 - 990)	563 (381 - 746)
Total dissaving	1,148 (795 - 1,502)	-	697 (372 - 1,022)	1,436 (902 - 1,971)	1,148 (795 - 1,502)
TB impact on social life, % (95% CI)					
Impact social life	46 (43 - 50)	15 (10 - 23)	37 (32 - 42)	44 (40 - 49)	42% (38 - 45)
TB impact on household finance, % (95% CI)					
1 = Richer	1.4 (0.76 - 2.6)	0 (0 - 3.4)	1.2 (0.64 - 2.2)	1.5 (0.55 - 3.6)	1.1 (0.43 - 2.4)
2 = Unchanged	26 (23 - 29)	40 (32 - 49)	28 (25 - 31)	28 (24 - 33)	28 (24 - 32)
3 = Poorer	55 (51 - 58)	50 (41 - 58)	54 (51 - 57)	52 (46 - 57)	55 (51 - 60)
4 = Much poorer	18 (15 - 21)	10 (5.9 - 17)	17 (14 - 19)	18 (15 - 23)	16 (13 - 19)

*Patients on first line TB treatment; **Patients on second line TB treatment; ***All patients on TB treatment

*Patients on first line TB treatment, **Patients on second line TB treatment, ***All patients on TB treatment

**Fig. 1** Proportion of households facing catastrophic costs due to TB at 10%, 20%, and 40% thresholds in Somalia (2024)

or no), and treatment delay (4 weeks or less versus more than 4 weeks).

Discussion

Despite the challenging operating environment, Somalia successfully conducted its first national survey to estimate the proportion of TB-related catastrophic costs

among patients receiving TB care and their households. The survey findings highlighted the extent and primary drivers of various costs incurred by patients undergoing TB treatment and their households, both before and during treatment. This establishes a baseline for estimating and monitoring the third leading indicator of the WHO End TB Strategy, enabling the government to effectively

Table 6 Risk factors associated with high catastrophic costs among patients in TB care and their households (Somalia, 2024)

Category	N	Odds Ratio	95% CI ¹	p-value	Adjusted OR ¹	95% CI	p-value
Age band	710						
<15		—	—		—	—	
15-49		0.67	0.35, 1.21	0.2	0.81	0.28, 2.09	0.7
50+		0.75	0.37, 1.43	0.4	1.02	0.34, 2.87	>0.9
Sex	710						
Female		—	—		—	—	
Male		0.84	0.60, 1.16	0.3	0.93	0.56, 1.54	0.8
Educational status	710						
No education		—	—		—	—	
Primary-Secondary		0.86	0.62, 1.19	0.4	0.94	0.57, 1.59	0.8
University		1.34	0.46, 4.87	0.6	1.41	0.32, 9.85	0.7
occupation	710						
Unemployed		—	—		—	—	
Employed		0.92	0.66, 1.27	0.6	1.14	0.67, 1.95	0.6
State of residence	710						
Banadir		—	—		—	—	
Galmudug		1.02	0.55, 1.90	>0.9	0.81	0.28, 2.33	0.7
Hirshabelle		1.02	0.58, 1.80	>0.9	0.51	0.20, 1.30	0.2
Jubba-Land		0.76	0.45, 1.29	0.3	0.38	0.14, 1.03	0.060
Puntland		2.17	1.22, 3.94	0.009	1.26	0.44, 3.64	0.7
Somaliland		2.09	1.20, 3.65	0.009	1.56	0.63, 3.76	0.3
Southwest		1.0	0.50, 2.02	>0.9	0.15	0.03, 0.72	0.019
Recorded HIV Status	710						
HIV negative		—	—		—	—	
HIV positive		0.46	0.09, 2.53	0.4	0.32	0.04, 2.85	0.3
Unknown		0.96	0.60, 1.58	0.9	2.34	0.88, 6.73	0.10
Category of facility	710						
Private		—	—		—	—	
Public		0.00		>0.9	0.00		>0.9
TB sensitivity	710						
DS-TB		—	—		—	—	
DR-TB		0.72	0.47, 1.12	0.14	0.57	0.31, 1.05	0.070
Household size	710	1.03	0.99, 1.07	0.2	1.02	0.97, 1.07	0.5
Social impact	710						
No		—	—		—	—	
Yes		1.08	0.79, 1.48	0.6	0.60	0.35, 1.03	0.066
Insurance status	710						
No insurance		—	—		—	—	
Insurance		2.01	0.91, 5.05	0.10	1.41	0.27, 10.7	0.7
Treatment delay	392						
4 week or less		—	—		—	—	
> 4 weeks		1.34	0.84, 2.20	0.2	1.73	0.99, 3.12	0.060

¹OR = Odds Ratio, CI = Confidence Interval

plan to eliminate catastrophic costs related to TB in Somalia, as outlined in its National Strategic Plan [17].

Furthermore, the survey evaluated the direct medical, direct nonmedical, and indirect costs related to a TB episode for both DS-TB and DR-TB in Somalia. The findings revealed that TB services are accessible at both public and private facilities. However, about 9 out of 10 participants in the survey received their TB treatment from public facilities, which aligns with routine program data [9]. For most assessed parameters, the demographic and clinical characteristics of individuals with DS-TB did not significantly differ from those with DR-TB, except that all DR-TB patients were receiving care at public health facilities and three-quarters were in the intensive phase of treatment during the interview, compared to less than half of those with DS-TB. According to the country's notification data, most participants were new TB cases; 9 out of 10 had documented their HIV status, indicating an insignificant TB/HIV co-infection rate [25].

Patients receiving treatment for TB encounter delays in accessing care and spend a considerable number of days hospitalized, underscoring an inadequate patient-centered care model. Typically, patients visit healthcare facilities no more than once before obtaining a diagnosis. However, it may take anywhere from 1 to 4 weeks after noticing initial symptoms, or 1- to 7-week post-diagnosis, to initiate TB treatment. These findings align with those from other studies [26, 27]. This study shows that the TB care model in Somalia often prolongs patient admissions, leading to considerable direct and indirect costs. For example, patients experienced substantial lengths of stay during their hospitalizations (covering both intensive and continuation phases) of up to 67 days, with some drug-resistant TB patients facing stays of up to 180 days [5, 6, 26, 28]. Furthermore, the average income reduction from before contracting TB to the time of the interview reached as high as 61%, highlighting the economic burden of TB and the essential services required for treatment.

Although TB services are available at no cost in Somalia, this survey revealed that as many as 68% of patients receiving TB care and their households incur catastrophic TB-related costs, undermining the country's efforts to alleviate the economic burden of TB on patients. This percentage is significant and comparable to findings from Myanmar (60%), Vietnam (63%), Laos (63%), Ghana (64%), Mongolia (69%), Niger (71%), and Nigeria (71%) [29–32]. Moreover, this figure exceeds those reported from several Eastern African nations, including Kenya (27%), Tanzania (45%), and Uganda (53%), as well as from other African countries such as Egypt (24.1%), Lesotho (19%), and South Africa (56%), along with some Asian countries like China (37.1%) and India (32.4%) [7, 29,

33] [5, 34, 35]. Furthermore, Somalia's figure is relatively similar to, yet higher than, those from other low-income countries, including Uganda (53%), Mali (49%), Burkina Faso (54%), and Niger (71%) [29]. Unlike findings from other studies, a greater proportion of individuals with DS-TB (69% [95% CI: 65%–73%]) faced catastrophic costs compared to those with DR-TB (62% [95% CI: 52%–71%]) [36]; however, this observed difference was not statistically significant. This may be attributed to the social support provided to individuals with DR-TB through the Global Fund grant, which helps cover travel and food expenses. Also, MSF directly pays for baseline and treatment monitoring tests and in-patient feeding for patients on second-line treatment at the DR-TB treatment centers in Hargeisa and Galkayo.

Our study found that the catastrophic costs of accessing TB services had far-reaching consequences for patients receiving TB care and their households. The average estimated household net income from labor-related activities decreased by 38% per month during the TB episode and is likely to decline further before treatment is completed. Additionally, TB significantly impacted the social life, finances, and overall well-being of nearly half of the study participants in various ways, particularly among those with DS-TB, which is higher than what was observed in Uganda and Kenya [7, 37]. Furthermore, just over two-thirds of participants and their households became poorer than they were before contracting TB, a rate greater than reported in other studies [24, 31]. To cope with this economic burden, nearly half of the participants reported taking loans or selling their assets, with two out of three participants taking loans and one out of three selling assets, consistent with findings from other studies [24, 30, 35].

Analysis to determine the risk of incurring high TB-related catastrophic costs indicates that the state of residence increases the likelihood of facing greater TB-related costs in Somalia. In this survey, TB care patients residing in the Southwest state had the highest odds of encountering TB-related catastrophic costs. Consistent with other reports, our study found no significant association between age, sex, education, or employment status, household size, social impact, insurance status, treatment delays, and TB-related catastrophic costs [27, 33, 38, 39].

Our study's findings fill a crucial gap by providing Somalia with data on the proportion of TB-affected households facing catastrophic costs, as well as baseline information to report and monitor the WHO End TB Strategy's recommended indicator regarding the percentage of patients in TB care and their households experiencing catastrophic expenses. It highlights significant programmatic gaps where routine program monitoring and supervision may not be effectively acknowledged,

even when implemented correctly. For example, this study suggests that the Somalia NTP reevaluate its TB care model, which systematically increases out-of-pocket costs for patients accessing TB services. Additionally, our research emphasizes the absence of social protection or health insurance for over 99% of patients in TB care, which may further illustrate the substantial burden of TB-related catastrophic costs and dissaving. Nonetheless, individuals with DR-TB benefit from various support systems that help reduce out-of-pocket expenses compared to those receiving DS-TB care. Many households reported that contracting TB had a considerable impact on their social life, well-being, and finances, underscoring the hidden burden this disease places on those affected by it [14, 40–42].

This study's protocol strictly adhered to WHO guidance on conducting TB cost surveys [14]. However, the study encountered certain limitations, which it navigated without compromising its integrity and quality. Participants from private health facilities accounted for less than 6%, consistent with the proportion of TB cases reported by these private facilities that offer directly observed treatment short-course (DOTS) services in Somalia. This may not represent a legitimate limitation but rather reflect the healthcare landscape in Somalia. Nonetheless, the low coverage of TB services in the private sector could affect the catastrophic TB cost outcomes for individuals accessing TB services there. Security was a significant concern in Somalia during the survey period, and ongoing conflict in six districts necessitated the exclusion of certain health facilities. This exclusion may have influenced the study results and limited the survey team's access to hard-to-reach communities that might be underserved. The study relied on participants' ability to recall their income, expenses, and cost history related to accessing TB services. Given that a substantial proportion of participants lacked formal education or had limited educational attainment, their ability to recall this information may have been impaired, potentially leading to recall bias.

Additionally, limited resources and the inability to conduct in-person training for data collectors and interviewers may have considerably impacted the data collection process, despite a quality assurance mechanism to improve the survey's data quality. The study faced challenges in effectively gathering and analyzing qualitative information regarding delays in service delivery, including diagnostic delays, treatment delays, and follow-up. This highlights the need for future studies to better comprehend the population's health-seeking behavior regarding TB and the health system factors contributing to delays in accessing care after first noticing TB symptoms, as well as during the diagnostic phase and the initiation of TB treatment.

Conclusions

This study found that individuals with TB and their households face a significant economic burden when accessing TB services in Somalia, and the provision of social protection remains suboptimal. Patients incur higher direct nonmedical costs than other types of expenses, particularly during the continuation phase of treatment. This situation forces patients to borrow or sell their assets, leaving them poorer than they were before contracting TB. The findings suggest that the NTP should review its current TB care model to promote ambulatory care and adopt a more differentiated approach, including establishing a sustainable and equitable social protection program for individuals with TB and their households.

Abbreviations

TB	Tuberculosis
Deff	Design effect
WHO	World Health Organization
RR/MDR-TB	Rifampicin-resistant/multidrug-resistant TB
MSF	Médecins Sans Frontières
TBMUs	TB Management Units
NTP	National TB Program
GDP	Gross domestic product
DR-TB	Drug-resistant/second-line TB
DS-TB	Drug-sensitive/first-line TB

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Authors' contributions

J.K., I.S.S., M.A.S., M.J.S., A.A.H., V.R., F.N., and M.A. conceptualized and designed the study and participated in data acquisition. All authors contributed to the interpretation of the study results. J.K., I.S.S., and S.B. conducted data analysis. J.K. and I.S.S. wrote the original draft of the manuscript. B.A., E.O., and A.H. substantively revised the manuscript. J.K., I.S.S., S.B., and E.O. further reviewed the manuscript in response to the reviewers' comments. All authors proofread and approved the manuscript.

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Data availability

The datasets generated and/or analyzed during the current study are not publicly available because they contain individual-level information that may compromise their confidentiality. The data are available from the corresponding author upon reasonable request. The analytic codes are available on GitHub: <https://github.com/stephenbalogun/TB-project> [21].

Declarations

Ethics approval and consent to participate

The study received approval from the Research and Ethical Committee at the Ministry of Health in Somalia, referenced as Ref/MOHHS/DGO/0982/December 2023. Written informed consent, along with unique survey numbers, was obtained from eligible participants through their signatures and thumbprints. Guardians of children under 15 years old provided written informed consent,

while adolescents who understood the purpose and procedures of the survey were able to give their own informed written consent. Consent was obtained voluntarily by the interviewer in a non-coercive manner, following an explanation provided in a language that the participants understood. Participants had the option to withdraw at any time; no incentives were offered, and their information remained confidential. Also, the research conformed to the principles of the Helsinki Declaration, which safeguards the well-being of survey participants.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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