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Original Article

Understanding the financial hardships faced by TB and HIV patients during the COVID-19 pandemic: a mixed-method study in Bandung and Yogyakarta, Indonesia

Nasser Fardousi[1], Srila Nirmithya Salita Negara[2], Yanri Wijayanti Subronto[2,3,4], Yusuf Ari Mashuri[2,5], Qinglu Cheng[6], Luh Putu Lila Wulandari[6], I Wayan Cahyadi Surya Distira Putra[2], Siska Dian Wahyuningtias[2], Ari Probandari[2,5], Hasbullah Thabrany[7], Virginia Wiseman[5,8,†], Riris Andono Ahmad[2,*], David Boettiger[6], Marco Liverani[8,9,10]

[1]Department of Infectious Disease Epidemiology and International Health, London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, United Kingdom
[2]Centre for Tropical Medicine, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Yogyakarta, Jl. Farmako Sekip Utara, Yogyakarta 55281, Indonesia
[3]Division of Tropical Medicine and Infectious Diseases, Department of Internal Medicine, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Jl. Farmako Sekip Utara, Yogyakarta 55281, Indonesia
[4]Dr. Sardjito General Hospital, Jl. Kesehatan Sendowo No.1, Yogyakarta 55281, Indonesia
[5]Department of Public Health, Faculty of Medicine, Universitas Sebelas Maret, Jl. Ir. Sutami 36A, Surakarta 57126, Indonesia
[6]Kirby Institute, University of New South Wales, Wallace Wurth Building (C27), Cnr High St & Botany St, UNSW, Kensington NSW 2033, Australia
[7]ThinkWell.Global, Plaza Bank Index Level11, Jalan MH Thamrin No. 57, Jakarta 10350, Indonesia
[8]Department of Global Health and Development, London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, United Kingdom
[9]School of Tropical Medicine and Global Health, Nagasaki University, 1-12-4 Sakamoto, Nagasaki City 852-8523, Japan
[10]Faculty of Public Health, Mahidol University, 420/1 Ratchawithi Rd, Khwaeng Thung Phaya Thai, Khet Ratchathewi, Krung Thep Maha Nakhon 10400, Thailand

*Corresponding author. Department of Biostatistics, Epidemiology and Population Health, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Jl. Farmako Sekip Utara, Yogyakarta 55282, Indonesia. E-mail: risandono_ahmad@ugm.ac.id
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Abstract

The COVID-19 pandemic had significant widespread financial impacts, resulting in decreased household income, increased unemployment, and disrupted health services. Despite the higher prevalence of infections of tuberculosis (TB) and human immunodeficiency virus (HIV) in poorer populations, research on the financial challenges faced by these populations during the pandemic is still limited. Indonesia recorded the highest COVID-19 cases in Southeast Asia (6 815 156) while contending with the dual burden of HIV and TB. This study investigates the factors influencing out-of-pocket (OOP) payments and catastrophic health spending during the pandemic, alongside patients' challenges and coping mechanisms in Bandung and Yogyakarta, Indonesia. We employed a parallel convergent mixed-methods approach, combining quantitative analysis of OOP costs with qualitative interviews. The determinants of OOP payments were analysed using a two-part cluster-robust regression model. Catastrophic health spending was defined as OOP payments exceeding 10% of a household's annual income. Data on OOP spending were recorded via diaries, while qualitative data were gathered from in-depth interviews with TB and HIV patients and healthcare workers from January to October 2022. The findings indicated that 5.13% [95% confidence interval (CI): 2.99–7.28] of households incurred catastrophically. The median household spent USD 8.48 OOP, with nonmedical expenses comprising the largest share (median USD 5.93). Key predictors of higher costs included facility location in Yogyakarta (OOP costs difference USD 23.84, 95% CI: 9.90–37.77, $P < .001$), seeking care from public hospitals (USD 17.37, 95% CI: 8.83–25.90, $P < .001$), and the absence of health insurance (USD 10.49, 95% CI: 2.40–18.58, $P = .011$). Patients reported that job losses during lockdowns exacerbated financial strain, while coping strategies documented included borrowing, family contributions, and selling assets. This is the first study to focus on OOP spending and the financial hardships experienced by TB and HIV patients in Indonesia during the pandemic, providing insights for targeted policy and preparedness efforts to alleviate the financial burden during large-scale public health crises.

Keywords: COVID-19; tuberculosis; HIV; financial hardship; Indonesia; mixed-methods

Key messages

- The COVID-19 pandemic caused a major economic recession and disrupted access to affordable TB and HIV health services. However, limited research has been conducted on financial hardships experienced by tuberculosis (TB) and human immunodeficiency virus (HIV) patients during the pandemic.
- We found that in Indonesia, TB and HIV patients experienced loss of income and catastrophic health costs, concentrated in poorer households, with transport costs accounting for the majority of out-of-pocket (OOP) expenses.
- We identified factors associated with increased OOP expenses: seeking secondary care, absence of health insurance, and facility location. Policymakers could alleviate the financial burden on households by developing targeted interventions that consider those factors.
- During global health crises, financial protection policies should aim to support poorer households and those affected by income loss, expanding coverage to include transport costs and other nonmedical expenses.

Introduction

In addition to a global health crisis, the COVID-19 pandemic caused significant economic and financial impacts on patients. The widespread economic recession increased unemployment and living expenses (ILO Monitor 2020). Access to affordable healthcare services for non-COVID-19 patients was impaired, as many health systems worldwide were reconfigured to respond to the pandemic (Prinja and Pandav 2020, International Association of Providers of AIDS Care 2022). The utilization of public health services declined due to challenges in accessing healthcare during the lockdown and fears of contracting the coronavirus. This decline was accompanied by an increase in demand for private health services and related out-of-pocket (OOP) health spending, as well as increased catastrophic spending (El-Khatib et al. 2020, Garg et al. 2022, Haakenstad et al. 2023).

During the pandemic, disruptions to tuberculosis (TB) and human immunodeficiency virus (HIV) healthcare services were reported globally (World Health Organization 2020a, Martin-Hughes et al. 2022, SeyedAlinaghi et al. 2023). In 2020, the World Health Organization (WHO) reported a significant decline in new TB case identification, coinciding with an estimated excess of 100 000 TB-related deaths linked to the pandemic's impact on healthcare services (World Health Organization 2021). Services for patients with HIV also experienced disruptions, which were associated with 650 000 deaths (UNAIDS 2022). At the same time, the number of people on HIV treatment grew more slowly than it had in over a decade (UNAIDS 2022).

Given the higher prevalence of TB and HIV infections in poorer populations, the pandemic may have aggravated the financial strain experienced by households affected by TB and HIV (Siroka et al. 2016, World Health Organization 2020b, Ghazy et al. 2022, Portnoy et al. 2023). Consequently, many international organizations warned against a singular focus on COVID-19. They called for the continuity of essential services, including TB and HIV care, as well as a better understanding of the economic impact of these challenges on affected patients (Hogan et al. 2020, Fuady et al. 2021).

Financial protection measures have been an integral part of TB and HIV control strategies to ensure sustained progress towards elimination targets (Gitahi-Kamau et al. 2015, Fuady et al. 2020). In its End TB strategy, the WHO called for 'bold' policies to provide social protection and poverty alleviation to TB patients (World Health Organization 2022). Prepandemic evidence showed that inequalities and financial barriers to accessing TB and HIV services contributed to worsening treatment outcomes for patients (Long et al. 2011, Fuady et al. 2020, Suryana et al. 2022). With the potential financial burden caused by the COVID-19 pandemic, more research is needed to inform robust protection policies to mitigate the impact on TB and HIV patients (Vanleeuw et al. 2022).

Indonesia, a country of around 282 million people in 2024, was severely impacted by the COVID-19 pandemic, with 6 815 156 confirmed cases and 161 923 deaths as of December 2023 (World Health Organization 2023a). Between March and September 2020, the number of people living in poverty increased by >875 000 people (BPS-Statistics Indonesia). TB and HIV services were disrupted (Caren et al. 2022, Fauk et al. 2023, Surendra et al. 2023, Mashuri et al. 2024 , Wulandari et al. 2024), potentially exacerbating the existing financial vulnerabilities of patients suffering from these diseases (Fuady et al. 2021). Even before the pandemic, Indonesian TB patients faced significant OOP spending, such as transport and food supplement costs, despite being covered by national health insurance (Fuady et al. 2019). Research indicated that in 2016, 36% of Indonesian households with TB patients spent over 20% of their income on TB-related treatment. However, this financial burden decreased between 2017 and 2018, with 25.5% of households spending this proportion of income on treatment (Fuady et al. 2018, McAllister et al. 2020).

Indonesia continued to provide existing social protection programs, mandated by its constitutional framework, for HIV and TB patients during the pandemic. Chief among these is the national health insurance program—the Jaminan Kesehatan Nasional (JKN)—launched in 2014 and aimed at achieving universal health coverage by 2019 (Pisani et al. 2017, Agustina et al. 2019). Other initiatives included funding for prevention and care for HIV and TB, along with providing free medications since 2007 (Lingkungan TDJPP dan P 2020). As the pandemic caused major disruptions to healthcare services and a substantial economic recession, there were concerns that TB and HIV patients may have faced aggravated financial adversities (Fuady et al. 2021).

Understanding the financial impact of COVID-19 on TB and HIV patients is essential for developing resilience-building strategies for TB and HIV programs and for strengthening overall health systems preparedness for public health emergencies. To date, however, research focusing on TB and HIV patients is still limited (Karjadi et al. 2021, Lestari et al. 2025), and deeper understanding is needed to explore the patterns and determinants of OOP costs, as well as their impact on financial hardship and the coping strategies employed during the pandemic. This study seeks to address these gaps by examining the extent and nature of these challenges in two major cities in Indonesia: Bandung and Yogyakarta. Specifically, it focuses on the incidence of catastrophic health spending (CHS) among TB and HIV patients, the key factors influencing OOP costs, and the lived experiences and coping mechanisms adopted by patients and their families.

Methods

Design

This study was part of a larger cohort study (DOMINO) aiming to investigate the impact of the COVID-19 pandemic on TB and HIV healthcare services in Indonesia (Mashuri et al. 2024, Wulandari et al. 2024). We employed a parallel convergent mixed-methods design, whereby qualitative and quantitative data were collected simultaneously, and findings were integrated at the interpretation level (Creswell and Creswell 2017). In this study, we conceptualized financial hardships both as a measurable burden, captured through catastrophic spending and OOP costs, and a perceived experience as described in the in-depth interviews (IDIs). Accordingly, the quantitative component aimed to measure the percentage of households with TB and HIV patients that incurred OOP payments exceeding 10% of their annual income during the pandemic. It also studied the factors influencing OOP healthcare spending among TB and HIV patients. The qualitative component aimed to explore the financial hardships and challenges experienced by TB and HIV patients and document any coping strategies employed. In keeping with a contiguous integration approach, we present the findings from the qualitative and quantitative components in separate sections in the Results section and triangulate the findings narratively in the Discussion section (Fetters et al. 2013).

Study settings

The study was conducted in Bandung and Yogyakarta, two major Indonesian cities in West Java Province and the Special Region of Yogyakarta, respectively. These cities were chosen as they have a similar governmental structure and experienced a large number of COVID-19 cases, exceeding 36 000 cases in Yogyakarta and 100 000 in Bandung in 2022, with a death toll of >1400 in Bandung and 1100 deaths in Yogyakarta between 2020 and 2022 (Pemerintah Kota Bandung 2023, Pemerintah Kota Yogyakarta 2023).

In 2022, the population in Bandung was 2 545 005, while in Yogyakarta, it was 449 890 (Central Bureau of Statistics Bandung City 2023, Regional Development Planning Agency Yogyakarta Region 2023). In the same year, the prevalence of HIV and TB in Bandung was 6695 cumulative HIV cases, while there were 14 541 TB cases (Bandung City Health Office 2022). In Yogyakarta, there were 1490 HIV cases and 1355 TB cases (Yogyakarta City Health Office 2023).

Data collection procedures

Cost diaries

Eligible patients included those who consented to participate in the study and were over 18 years old, had a diagnosis of either HIV or new drug-susceptible TB infection, linked to a public or private hospital or community healthcare centres (Pusat Kesehatan Masyarakat, abbreviated as 'puskesmas'), and experienced an interruption of care as identified by a healthcare professional. We defined 'interruption of care' as scenarios where patients faced reduced access to, availability of, or affordability in service delivery due to pandemic-related factors (Mashuri et al. 2024). Data were collected between January and August 2022.

After participants consented, they were provided with diaries and an aide-memoire comprising a list of cost categories, adapted from a WHO survey tool (WHO Global TB Programme 2015) (see Supplementary Appendix 1). The participants were asked to keep cost records related to their visits to health facilities as part of their treatment for 6 months or whenever their treatment concluded. More specifically, we asked participants to keep records of their OOP direct costs (both medical and nonmedical) net of any reimbursement. Medical costs included consultations, pharmaceuticals, diagnostic fees (such as laboratory tests and imaging), and expenses incurred from visiting other providers, such as community pharmacies, related to disease treatment. Nonmedical costs refer to expenses that are not directly related to the medical treatment or healthcare services received by a patient but are nonetheless incurred while seeking medical care. A comprehensive list of all the included cost categories, along with other categories commonly reported in the literature, is provided in Supplementary Appendix 2. These included travel expenses to the health facility, accommodation, and food supplements. The advantage of using diaries is their ability to capture costs over a longer period while minimizing recall bias, often experienced with questionnaires (Wiseman et al. 2005). The researchers followed up with patients by phone every 2 weeks to collect data recorded in the diaries.

To investigate the determinants of OOP costs, we collected baseline data in keeping with Andersen's framework for determinants of healthcare utilization (Andersen and Newman 2005). These included three categories: predisposing factors (age, sex, employment, marital status, and district), enabling factors (insurance status, income, facility type), and need factors (disease type, hospitalization). The household income question prompted 10 ranges of income spread evenly to cover any income between 0 and above 10 000 000 Indonesian Rupiah (IDR), equivalent to USD 673, with each range covering 1 million IDR. Baseline characteristic data collection was conducted by trained local researchers using a questionnaire designed for this purpose.

Two researchers piloted the data collection tools in a comparable facility with five patients. All diaries and aide-memoires were written in Bahasa. We converted costs and income to USD using the exchange rate provided by the World Bank for 2022: 1 USD = 14 849.9 IDR (World Development Indicators | DataBank).

In-depth interviews

IDIs took place between April and October 2022 at health facilities in Bandung and Yogyakarta. The sample participants were selected purposefully during consultation with health staff in the facilities and included HIV patients, TB patients, and healthcare workers (HCWs). Participants in the qualitative interviews were not the same individuals as those who took part in the cost diary study. IDIs were conducted face-to-face by a researcher trained in social research methods and a native Bahasa speaker in Indonesia. The question guide explored the impact of COVID-19 on patients' finances, treatment costs, and strategies to cope with these impacts. Lasting between 30 and 60 min, IDIs started with obtaining informed consent from the interviewees and took place in a private area in a community health centre to ensure confidentiality. The interviews were recorded with participants' permission, transcribed verbatim, and translated into English. A local researcher from the team piloted the interview questions with patients in another facility, which was similar to the data collection settings in terms of geographical location and facility characteristics.

This study was approved by the ethics committees of the authors' institutes.

Analysis

Statistical analysis

We present categorical data as frequencies and percentages. For OOP cost descriptive analysis, we present the breakdown of cost data using the median with the interquartile range (IQR), as the data were non-normally distributed. We used the Mann–Whitney and Kruskal–Wallis nonparametrical tests for statistical significance between groups at a P-value <.05. All analyses were conducted using STATA version 18 (StataCorp, College Station, TX, USA).

Determinants of out-of-pocket costs

To investigate the determinants of health costs, we implemented a two-part regression model, using a standard error that is robust to the clusters in our dataset (i.e. the health facility). We selected the two-part model (TPM) due to the distributional characteristics of our cost data, which included a large number of zero observations and a positively skewed distribution among nonzero values (Supplementary Appendix 3)—features commonly observed in healthcare expenditure data. The TPM allows for the separate modelling of the likelihood of incurring any cost and the magnitude of cost among those with positive expenditures (Frondel and Vance 2012, Deb and Norton 2018). This modelling strategy is widely applied in the health economics literature, particularly in contexts where the decision to incur any expenditure is independent of the amount to be spent. This is often the case with OOP health spending, where the primary driver for paying is health status (Egede et al. 2016 , Zhang et al. 2018, Zhao et al. 2020, Chowdhury and Goli 2025).

In our study, we used a logit model to estimate the probability of incurring positive costs versus no costs for all patients in our sample (Belotti et al. 2015). Next, we used a generalized linear model (GLM) on the subset of households that made any OOP payments, applying a gamma distribution with a logarithmic link function, as this selection improved the goodness-of-fit according to the Akaike Information Criterion (Supplementary Appendix 4). The overall effect—representing the OOP cost difference associated with a given determinant—was estimated by multiplying the probability of a patient paying any costs (from the logit model) by the expected mean value obtained from modelling the subset of patients who incurred healthcare costs (from the GLM).

To further confirm the appropriateness of our GLM specifications for the second part of the TPM, we conducted two diagnostic tests. The modified Park test was used to determine the appropriate family distribution by examining the relationship between the mean and variance of the cost data (Manning and Mullahy 2001). The Box–Cox test was employed to identify the most suitable link function for the GLM by estimating the transformation of the dependent variable that best linearizes the model (Box and Cox 1964). Both tests supported the use of a gamma distribution with a log link, and the results are provided in Supplementary Appendix 4.

For the multivariate analysis, we selected determinants from the univariate analyses that were statistically significant (Supplementary Appendix 5). Since wealthier households typically have a greater capacity to pay (de Siqueira Filha et al. 2022), we classified income into quintiles and controlled for it in all our models.

Catastrophic health spending

CHS, which evaluates the burden of OOP payments on a given household, was defined according to the 3.8.2 indicator of the Sustainable Development Goals (United Nations 2019). The indicator considers any OOP spending (i.e. the sum of any direct medical and nonmedical costs) that exceeds 10% of the household's annual income as catastrophic (Fattah et al. 2023). To calculate the annual OOP spending, we used the appropriate multiplier based on the duration of follow-up. For example, we multiplied the cost data by two for participants who were followed up for 6 months. Sensitivity tests were conducted by estimating the CHS at the 5%, 10%, 15%, and 20% thresholds of annual household income. Given that the variable for household income in our data was categorical, we assigned patients to the midpoint of the income range they selected (Sweeney et al. 2018). Again, we tested the sensitivity of the income variable by producing two estimates of CHS incidence, corresponding to the lower and upper bounds of the income range to account for uncertainty in income data. For example, we calculated the CHS incidence for patients whose income fell between 1 and 2 million IDR, using the denominators of 1 (lower bound), 1.5 (midpoint), and 2 million (upper bound). For missing income entries, we used the median income from households where the primary earner holds the same job as the household's missing income.

Qualitative analysis

Transcribed interviews were reviewed and coded iteratively using NVivo 14 (QSR International Ltd). We followed a thematic analysis approach to identify the themes following the approach proposed by Braun and Clarke (2006), which allowed for the identification of both deductive and inductive themes. Themes were deductively identified related to the financial impact of the pandemic on individuals and healthcare services. Themes were also identified inductively as they emerged from the data through open coding, capturing further aspects of the financial impact of the pandemic, such as coping strategies. Two researchers conducted pair coding, discussing and agreeing on discordant codes to ensure reliability. Data coding was conducted concurrently with data collection and stopped when our sample reached theoretical saturation.

Results

Out-of-pocket costs

Sample characteristics

Four hundred and fifty patients were invited to participate in the cost diary study—100 HIV patients and 350 TB patients. Of those, 94 HIV patients and 315 TB patients agreed to participate. Income data were available for 314 participants (77%). Females accounted for 42% of the sample. Patients were recruited from 80 puskesmas and 8 public hospitals in Bandung, and 18 puskesmas and 4 public hospitals in Yogyakarta. Most participants (75%) were of working age (25–64 years). The majority of our patients had TB (77%), while 94 (23%) were HIV-positive but had no co-infection. Only three patients (<1%) confirmed they were hospitalized by the end of the data collection period. Most patients (75%) were insured through the JKN and had paid for their

Table 1. Descriptive statistics of sampled households ($N = 409$).

	N	%
Sex		
Male	236	57.70
Female	173	42.30
Age group		
15–24	79	19.32
25–34	125	30.56
35–44	82	20.05
45–54	57	13.94
55–64	44	10.76
65 plus	22	5.38
Income quintiles		
Poorest	87	21.27
Poorer	128	31.30
Middle	97	23.72
Rich	62	15.16
Richest	35	8.56
Disease		
TB	315	77.02
HIV	94	22.98
Participant's location		
Yogyakarta	90	22.00
Bandung	319	78.00
Facility type		
Public hospital	75	18.34
Puskesmas	322	78.73
Private facility	12	2.93
Insurance status		
Insured	307	75.06
Uninsured	102	24.94
Insurance type		
Uninsured	102	24.94
JKN (paid by government)	210	51.34
JKN (self-paid)	96	23.47
Private insurance	1	0.24
Having paid work?		
Yes	225	55.01
No	184	44.99
Hospitalization		
Yes	3	0.73
No	375	91.69
Don't recall/unsure	31	7.58
Marital status		
Single	157	38.39
Married	227	55.50
Divorced	15	3.67
Widowed	10	2.44

JKN, Jaminan Kesehatan Nasional, the national health insurance scheme.

insurance. In terms of income, almost half of the households in our sample (49%; $n = 156$) earned between IDR 2 000 000 (~USD 135) and IDR 4 000 000 (~USD 270) per month. The poorest households quintile (21%) earned less than 2 million IDR per month, while the richest households (9%) earned >5 million IDR per month (Table 1).

Our sample's median OOP cost (medical and nonmedical) was USD 8.48 (IQR: 2.76–21.89). Nonmedical costs constituted the largest share, with a median of USD 5.99 (1.95–11.72), particularly for transport, at USD 2.56 (0.61–6.06) (Table 2). Seeking care from healthcare providers other than puskesmas or public hospitals was the chief driver of medical costs.

Incidence of catastrophic spending

At a threshold of 10%, we estimated a CHS incidence of 5.13% [95% confidence interval (CI): 2.99%–7.28%]. By varying the value of household income, CHS incidence fell between 2.93% (95% CI: 1.29%–4.58%) (assuming the higher bound of the range) and 9.54% (95% CI: 6.68%–12.39%) (for the lower bound) (Fig. 1). Using a 20% threshold value, the incidence ranged between 0.73% (95% CI: −0.10% to 1.56%) and 6.60% (95% CI: 4.18%–9.02%). Households in the poorest quintile had the highest incidence of catastrophic spending (Fig. 2).

Table 2. OOP costs incurred.

	Median USD (IQR)
Medical costs	
Total	0.20 (0.00–7.41)
Consultation	0.00 (0.00–0.00)
Radiography	0.00 (0.00–0.00)
Laboratory	0.00 (0.00–0.00)
Other medical procedures	0.00 (0.00–0.00)
Medication	0.00 (0.00–0.00)
Visit to other health facilities	0.00 (0.00–0.65)
Medical costs not covered	0.00 (0.00–0.00)
Administration/registration fees	0.00 (0.00–0.00)
Nonmedical costs	
Total	5.93 (1.82–11.58)
Transport	2.56 (0.61–6.06)
Food	0.67 (0.00–2.69)
Accommodation	0.00 (0.00–0.00)
Other nonmedical spending	0.00 (0.00–0.00)
Supplements and over-the-counter items	0.00 (0.00–0.00)
Total direct costs	
Overall	8.48 (2.76–21.89)

Determinants of out-of-pocket costs

Figure 3 presents the estimated differences in OOP payment (in USD) for each determinant, combining results from the logit and GLMs. The complete set of adjusted estimates is provided in Tables 3–5 for medical, nonmedical, and total direct costs, respectively.

Facilities' location was a key determinant of OOP payments during the pandemic. Households seeking care from a facility located in the city of Yogyakarta incurred higher overall direct costs than those in Bandung (estimated OOP cost difference: USD 23.84, 95% CI: 9.90–37.77, P-value = .0008) (Table 5). This effect was consistent across medical costs (USD 20.08, 95% CI: 6.35–33.82, P-value = .0041) (Table 3) and nonmedical costs (USD 6.99, 95% CI: 2.61–11.37, P-value = .0018) (Table 4).

Another determinant was the facility type, as patients seeking care from a public hospital incurred higher OOP payments than those seeking care from puskesmas (USD 17.37, 95% CI: 8.83–25.90, P-value < .001). Insurance appeared to have a protective effect from incurring medical costs but was not associated with nonmedical costs. Uninsured patients incurred higher overall costs (medical and nonmedical) (USD 10.49, 95% CI: 2.40–18.58, P-value = .011). The type of disease (HIV vs. TB) was not associated with a significant difference in OOP payments effect size(USD 2.78, 95% CI: −5.16 to 10.71, P-value = .4925) (Table 5).

Perceived financial impact of the pandemic

Participants in the qualitative interviews comprised eight TB patients (one male and seven females), eight HIV patients (six

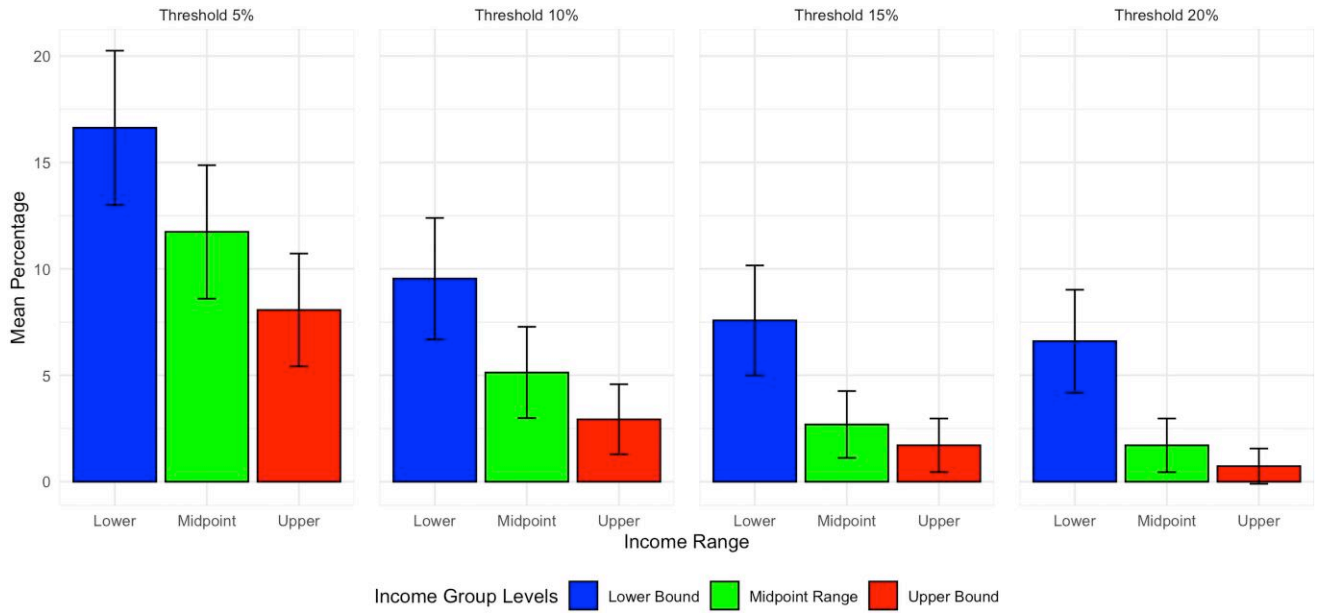

Figure 1. Percentage of households incurring catastrophic health spending, using the lower, mid, and upper bound of the income range. Blue bars represent the share of households incurring catastrophically when the lower bound of the income range is used as the denominator; green for the middle point of the income; and red for the upper bound of the income range.

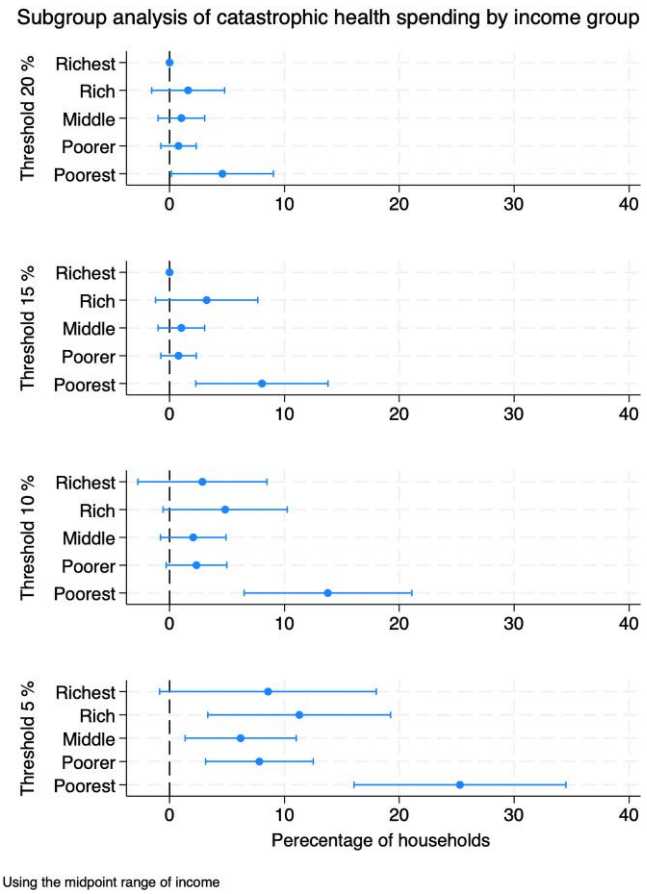

Figure 2. Subgroup analysis of catastrophic health spending by income quintiles using the midpoint of the income range.

males and two females), and two HCWs (see Supplementary Appendix 6).

Impact on livelihood

Even before the pandemic, participants reported experiencing financial difficulties after being diagnosed with TB or HIV, especially if their symptoms had already worsened before having a diagnosis. For instance, an HIV patient recalled how the shock of receiving the diagnosis discouraged him from working.

> 'I was shocked, I was in denial. I didn't leave my room for almost a week. Crying and eating are difficult, and diarrhoea continues. Well, eventually, my work was neglected. In the first two or three months, I lost all my jobs. Then I started from the beginning again, from zero again, looking for clients again' (HIV 02).

After the onset of the pandemic, these challenges became more severe for some participants. The financial impact of the pandemic was primarily felt through loss of income, with many businesses being forced to close, especially in the hospitality sector. Participants who were able to keep their jobs experienced a decrease in their earnings due to lower consumer demand and companies being forced to implement cost-cutting measures.

> 'During the pandemic, I really felt I was earning less. For example, the minimum wage in Yogyakarta is 1.8 [million IDR]. But [during the pandemic] you could receive at most 900, 800 [thousand IDR] a month.

> Tourism has really plummeted. All those who have booked finally cancelled everything, right? So we also lowered prices from March [2020]' (HIV 03).

Many of those who had lost their jobs moved back to their homes in the countryside. One participant explained, 'Well,

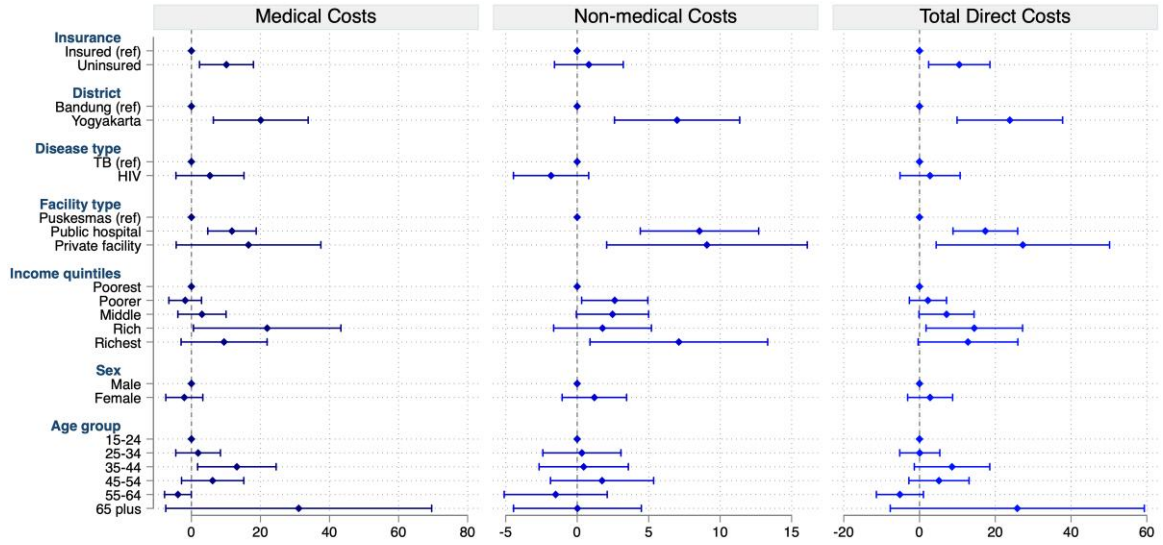

Figure 3. Determinants of OOP healthcare costs (combined effects from TPM for medical, nonmedical, and total direct costs). Bars indicate estimated difference in mean OOP costs (USD) with 95% CIs.

Table 3. Determinants of direct medical costs (estimates from the TPM).

	Logistic		GLM		Combined	
	aOR (95% CI)	*P*-value	Coefficient (95% CI)	*P*-value	OOP costs difference[a] (95% CI)	*P*-value
Disease						
TB	Ref		Ref		Ref	
HIV	1.02 (0.53 to 1.98)	.9430	0.41 (−0.24 to 1.07)	.2176	5.37 (−4.48 to 15.23)	.2854
Participant's location						
Bandung	Ref		Ref		Ref	
Yogyakarta	5.15*** (2.77 to 9.57)	.0000	0.96*** (0.42 to 1.49)	.0005	20.08** (6.35 to 33.82)	.0041
Income quintiles						
Poorest	Ref		Ref		Ref	
Poorer	1.48 (0.78 to 2.84)	.2322	−0.36 (−0.97 to 0.25)	.2453	−1.80 (−6.52 to 2.93)	.4559
Middle	2.53* (1.24 to 5.17)	.0106	0.11 (−0.60 to 0.83)	.7563	3.06 (−3.93 to10.05)	.3914
Rich	1.91 (0.84 to 4.31)	.1211	1.17** (0.35 to 1.99)	.0049	21.94* (0.58 to 43.31)	.0441
Richest	0.97 (0.38 to 2.48)	.9447	0.80 (−0.01 to 1.60)	.0522	9.46 (−2.99 to 21.92)	.1364
Facility type						
Puskesmas	Ref		Ref		Ref	
Public hospital	2.56** (1.35 to 4.87)	.0041	0.65** (0.20 to 1.10)	.0043	11.75** (4.74 to 18.76)	.0010
Private facility	4.74 (0.85 to 26.40)	.0757	0.77 (−0.14 to 1.68)	.0977	16.54 (−4.41 to 37.49)	.1218
Insurance status						
Insured	Ref		Ref		Ref	
Uninsured	7.71*** (4.17 to 14.25)	.0000	0.35 (−0.10 to 0.79)	.1242	10.15* (2.33 to 17.97)	.0110
Sex						
Male	Ref		Ref		Ref	
Female	0.91 (0.55 to 1.50)	.7097	−0.16 (−0.63 to 0.31)	.5154	−2.06 (−7.42 to 3.30)	.4509
Age group						
15–24	Ref		Ref		Ref	
25–34	0.81 (0.41 to 1.61)	.5468	0.30 (−0.48 to 1.09)	.4497	1.94 (−4.53 to 8.41)	.5570
35–44	1.57 (0.75 to 3.28)	.2295	0.96** (0.23 to 1.69)	.0096	13.17* (1.80 to 24.53)	.0232
45–54	1.59 (0.70 to 3.59)	.2679	0.53 (−0.25 to 1.32)	.1850	6.15 (−2.86 to 15.17)	.1811
55–64	0.74 (0.30 to 1.79)	.4998	−0.75 (−1.51 to 0.01)	.0541	−3.90* (−7.78 to −0.03)	.0484
≥65	2.34 (0.73 to 7.52)	.1541	1.53** (0.44 to 2.62)	.0060	31.09 (−7.43 to 69.60)	.1137
N	409		223		409	

aOR, adjusted odds ratio; GLM, generalized linear model.
*$P \leq 0.05$, **$P \leq 0.01$, ***$P \leq 0.001$.
[a]In USD.

what's the point of being in Bandung? How can I pay my rent if I don't work? It's better to go home' (HIV 06). Self-employed people were especially vulnerable as they did not have any social protection, and there were fewer job opportunities. Many patients had to accept lower-grade jobs to secure some source of income:

Table 4. Determinants of direct nonmedical costs (estimates from the TPM).

	Logistic		GLM		Combined	
	aOR (95% CI)	*P*-value	Coefficient (95% CI)	*P*-value	OOP costs difference[a] (95% CI)	*P*-value
Disease						
TB	Ref		Ref		Ref	
HIV	2.48 (0.66 to 9.38)	.1805	−0.25 (−0.55 to 0.04)	.0870	−1.83 (−4.46 to 0.80)	.1736
Participant's location						
Bandung	Ref		Ref		Ref	
Yogyakarta	3.83* (1.08–13.61)	.0379	0.56*** (0.26 to 0.86)	.0003	6.99** (2.61–11.37)	.0018
Income quintiles						
Poorest	Ref		Ref		Ref	
Poorer	1.31 (0.53 to 3.25)	.5536	0.29* (0.03 to 0.56)	.0318	2.63* (0.31 to 4.94)	.0262
Middle	2.24 (0.75 to 6.66)	.1480	0.24 (−0.05 to 0.53)	.1025	2.47 (−0.05 to 5.00)	.0551
Rich	1.10 (0.36 to 3.32)	.8700	0.21 (−0.18 to 0.61)	.2829	1.77 (−1.65 to 5.19)	.3099
Richest	2.21 (0.43–11.27)	.3396	0.64** (0.17 to 1.11)	.0077	7.11* (0.90–13.33)	.0249
Facility type						
Puskesmas	Ref		Ref		Ref	
Public hospital	8.73* (1.14–66.90)	.0371	0.65*** (0.38 to 0.92)	.0000	8.56*** (4.42–12.70)	.0001
Private facility	Ref		0.78*** (0.35 to 1.20)	.0003	9.08* (2.06–16.09)	.0112
Insurance status						
Insured	Ref		Ref		Ref	
Uninsured	0.58 (0.27 to 1.26)	.1684	0.13 (−0.11 to 0.37)	.2845	0.82 (−1.59 to 3.22)	.5064
Sex						
Male	Ref		Ref		Ref	
Female	1.22 (0.59 to 2.53)	.5835	0.11 (−0.12 to 0.34)	.3443	1.20 (−1.05 to 3.46)	.2966
age group						
15–24	Ref		Ref		Ref	
25–34	1.33 (0.47 to 3.72)	.5913	0.02 (−0.27 to 0.30)	.9115	0.33 (−2.40 to 3.06)	.8141
35–44	0.85 (0.31 to 2.35)	.7508	0.06 (−0.26 to 0.39)	.7050	0.46 (−2.67 to 3.58)	.7744
45–54	1.06 (0.31 to 3.60)	.9301	0.17 (−0.17 to 0.51)	.3294	1.74 (−1.87 to 5.35)	.3446
55–64	1.01 (0.30 to 3.46)	.9833	−0.18 (−0.62 to 0.26)	.4177	−1.51 (−5.11 to 2.10)	.4128
≥65	1.04 (0.19 to 5.85)	.9626	−0.00 (−0.48 to 0.47)	.9960	0.02 (−4.45 to 4.49)	.9940
N	409		370		409	

aOR, adjusted odds ratio; GLM, generalized linear model.
*$P \leq 0.05$, **$P \leq 0.01$, ***$P \leq 0.001$.
[a]In USD.

> 'I don't have a steady income right now. I need a job. I work for my relatives too. Sometimes I help sell food. What people tell me to do, I just do it, I just do it' (HIV 07).

> 'In terms of economic impact, one of the costs is because I used to have other side jobs. After the pandemic, I didn't have a side job. So my income is mediocre and very minimal. It's all lacking' (HIV 06).

Furthermore, lockdown limited patients' ability to go to work, as illustrated in the following quotation from an interview with an HCW.

> 'Well, one more thing about that [self-isolation]. After all, they have to self-isolate. It's been a public complaint that with this self-isolation, they are limited because they have to make a living and so on. That is. It's really annoying for them' (HCW TB 05).

Impact on care and treatment

The financial impact of COVID-19 reduced the participants' ability to pay for healthcare expenses not covered by JKN insurance, such as transport costs and parking fees, leading some to forgo visiting a health facility.

> 'Patients can't even eat, and they don't have the money to travel to the health centre' (HCW TB 05).

Although the national insurance scheme covered the cost of medicines, i.e. antiretrovirals (ARVs), participants with HIV reported they still had to pay for one laboratory test, i.e. CD4 cells count, some over-the-counter medicines, and food supplements, which were not included in the HIV treatment plan. TB patients reported that their national health insurance covered many aspects of treatment, including laboratory tests (e.g. sputum tests) and imaging (e.g. chest X-rays). For TB patients, the national health insurance also included medicines to treat symptoms (e.g. antitussives for cough or multivitamins for weakness). Furthermore, TB and HIV patients reported incurring OOP costs such as registration fees, food supplements, and any medicines that were out of stock in health facilities.

> '[the patient] can't come here; he can't pay for registration' (HCW HIV 07).

The JKN covered participants working in the formal sector for treatment. However, this meant that those who lost their job during the pandemic became subsequently ineligible for national health insurance, aggravating the financial burden of COVID-19. Furthermore, stigma played a negative role in OOP for some HIV patients, especially those disqualified from employer's insurance. For example, treatment for HIV is offered free of charge in puskesmas; however, if the facility was near patients' homes, some either chose not to

Table 5. Determinants of total direct costs (estimates from the TPM).

	Logistic		GLM		Combined	
	aOR (95% CI)	*P*-value	Coefficient (95% CI)	*P*-value	OOP costs difference[a] (95% CI)	*P*-value
Disease						
TB	Ref		Ref		Ref	
HIV	0.64 (0.15 to 2.81)	.5522	0.15 (−0.21 to 0.51)	.4178	2.78 (−5.16 to 10.71)	.4925
Participant's location						
Bandung	Ref		Ref		Ref	
Yogyakarta	8.20* (1.03 to 65.39)	0.0469	0.94*** (0.55 to 1.33)	.0000	23.84*** (9.90 to 37.77)	.0008
Income quintiles						
Poorest	Ref		Ref		Ref	
Poorer	3.24 (0.99 to 10.59)	.0515	0.09 (−0.23 to 0.41)	.5829	2.22 (−2.68 to 7.11)	.3752
Middle	7.42* (1.48 to 37.04)	.0146	0.34 (−0.05 to 0.72)	.0863	7.13 (−0.14 to 14.40)	.0547
Rich	3.69 (0.71 to 19.27)	.1221	0.64** (0.16 to 1.13)	.0094	14.46* (1.72 to 27.19)	.0261
Richest	5.17 (0.59 to 45.48)	.1385	0.58* (0.03 to 1.13)	.0394	12.78 (−0.37 to 25.94)	.0569
Facility type						
Puskesmas	Ref		Ref		Ref	
Public hospital	3.78 (0.46 to 30.94)	.2144	0.70*** (0.38 to 1.02)	.0000	17.37*** (8.83 to 25.90)	.0001
Private facility	1.00		0.99*** (0.41 to 1.57)	.0009	a 27.27* (4.38 to 50.16)	.0195
Insurance status						
Insured	Ref		Ref		Ref	
Uninsured	1.70 (0.46 to 6.36)	.4291	0.46** (0.16 to 0.76)	.0026	10.49* (2.40 to 18.58)	.0110
Sex						
Male	Ref		Ref		Ref	
Female	0.70 (0.25 to 1.94)	.4922	0.15 (−0.13 to 0.43)	.2996	2.79 (−3.15 to 8.73)	.3569
Age group						
15–24	Ref		Ref		Ref	
25–34	0.75 (0.19 to 2.96)	.6811	0.01 (−0.31 to 0.33)	.9409	0.06 (−5.23 to 5.35)	.9833
35–44	1.14 (0.23 to 5.61)	.8738	0.42 (−0.03 to 0.87)	.0679	8.58 (−1.38 to 18.53)	.0912
45–54	0.87 (0.17 to 4.56)	.8683	0.28 (−0.13 to 0.68)	.1802	5.13 (−2.81 to 13.07)	.2054
55–64	0.89 (0.16 to 4.87)	.8945	−0.38 (−0.85 to 0.09)	.1155	−5.19 (−11.40 to 1.02)	.1016
≥65	0.94 (0.08 to 10.53)	.9622	0.95* (0.12 to 1.78)	.0245	25.80 (−7.73 to 59.34)	.1315
N			389.00			

aOR, adjusted odds ratio; GLM: generalized linear model.
*$P \leq .05$, **$P \leq .01$, ***$P \leq .001$.
[a]In USD.

take ARVs, travelled to more distant puskesmas, or paid OOP in a private facility. One health worker in Bandung explained

> 'There is also an economic factor. Those who used to work then don't work. If we go to the puskesmas using BPJS, we have to be open. Instead of going to the puskesmas for this, it's better not to take medicine. That's how it is. Because not all patients want to be open to others' (HCW HIV 07).

Mitigation strategies

Patients adopted several strategies to cope with the financial difficulties caused by the pandemic. Some patients mentioned using savings, while others were fearful of borrowing and rather relied on pawning valuable items.

> 'even though it's hard, I don't dare to borrow money. Even though we don't have anything, I don't get into debt' (HIV 07).

> 'I always prepare for the unexpected in the future. The pandemic is one of the unexpected plans. Who knew there was a COVID-19 like that right. Yes, maybe from there. Maybe I saved it for something like this' (HIV 06).

Some patients relied on relatives' support to cover part of the treatment costs or borrowed from them.

> 'The first TB check-up at the hospital was paid for by my uncle. Then I had a shortness of breath and then used the nebuliser. The equipment and medicine were bought by my brother' (TB 04).

Other participants had savings or employed coping mechanisms, such as selling their valuables.

> 'There is an impact but it's not like people who immediately snap. Some have sold cars, sold this. For me, thank God, I still have enough. I'm grateful. Even though it's not as much as it used to be, thank God I didn't have to sell [my car]' (TB 03).

Discussion

During public health crises, health systems must be prepared to ensure the provision of financial protection schemes to households affected by infectious diseases associated with poverty, such as TB and HIV. Our study provides key insights into financial hardships faced by households with TB- and HIV-affected patients in Indonesia during the COVID-19 pandemic, highlighting potential areas for policies and preparedness efforts. To our knowledge, this is the first study to focus on financial hardships experienced by TB and HIV patients in Indonesia during the pandemic, capturing both measured and perceived burdens.

Our findings indicate that the COVID-19 pandemic had a worsening effect on patients' finances, primarily due to loss

of income, lack of health insurance, and increased nonmedical payments. Between 2.9% and 9.5% of the households in our sample incurred OOP payments that exceeded 10% of the household's annual income during the pandemic in 2022. Both qualitative and quantitative findings showed that nonmedical costs, mainly transport, drove OOP spending and hindered care-seeking behaviour.

Our findings on nonmedical costs are broadly consistent with those reported in a previous study conducted during the pandemic (Lestari et al. 2025), which estimated a median of USD 8.22 [IQR: 4.80–13.68] in a sample of Indonesian TB patients, compared to USD 5.93 (IQR: 1.82–11.58) in our sample of TB and HIV patients. However, there is a notable divergence in medical costs: while we found a median of just USD 0.20 (IQR: 0.00–7.41), the earlier study reported substantially higher median medical OOP costs of USD 22.29 (IQR: 8.91–47.59). This discrepancy likely reflects differences in sample composition and cost inclusion criteria. Specifically, the previous study focused on pretreatment costs, including COVID-19 tests as part of the medical expenses, whereas our cost diaries captured treatment-related spending only. Furthermore, their sample comprised nearly 90% participants who first sought care from informal or private providers—settings where costs are typically higher and less reimbursable—whereas most of our participants were recruited from public facilities, such as puskesmas, where services are often subsidized or free. Taken together, the two studies suggest that while nonmedical expenses such as transport are a consistent burden across settings, medical costs can vary substantially depending on where care is sought, especially during the pretreatment phase, underscoring the need for targeted financial protection strategies across both domains.

Despite the importance of benchmarking our findings on catastrophic spending incidence and OOP costs against pre-pandemic levels, we encountered significant challenges in identifying suitable studies for comparison. A review of existing literature revealed that prior studies employed varying methodologies, significantly hindering direct comparison. These differences included variations in the definitions of catastrophic spending, the threshold levels used, and the population subgroups analysed. Moreover, many studies utilized different data sources and timeframes, leading to inconsistencies in the measurement of CHS. For example, TB-specific studies in Indonesia reported a catastrophic spending incidence of 36% (Fuady et al. 2018) and 26.5% (McAllister et al. 2020) in drug-susceptible TB patients between 2016 and 2018. However, it should be noted that those studies included indirect costs and used a different cut-off point of 20%. As for national surveys, the World Bank and the WHO estimated that the national incidence of CHS in Indonesia was 2.33% and 1.97% in 2020 and 2021, respectively (World Health Organization 2023b), while a household panel study reported an incidence rate of 4.4% in 2019 (Fattah et al. 2023). Our study is not directly comparable to these prior surveys, as it includes only households with TB or HIV. Finally, a study collected data on OOP costs in a sample of TB, HIV, and coinfected patients in 2018 (Idrus et al. 2024). Again, the sample's composition varied markedly compared to ours, as 54% of the households were uninsured, versus 25% in our study, which likely gave rise to OOP costs in that study.

We found a strong association between the healthcare facility's location and OOP payments. Patients whose facility is located in Yogyakarta incurred higher medical and nonmedical costs than those in Bandung. One possible reason for this may be that Yogyakarta's tourism sector—one of the largest in the country—was disproportionately affected during the pandemic, causing many people to leave the city and return to their families in rural areas (Rahmat 2022, Saputri et al. 2022, Simatupang 2024). Patients, however, still had to travel back to the city to access specialized clinics and hospitals, incurring additional travel costs. We did not find a significant difference between OOP costs incurred by HIV and TB patients. However, the IDIs revealed that HIV patients incurred laboratory test fees, whereas TB patients were reimbursed for diagnostics. We also found that insurance was protective against medical costs, highlighting a need to extend financial protection measures to cover nonmedical items. In Indonesia, TB and HIV services are delivered through both national programmes and the JKN national insurance scheme. While public TB/HIV programmes offer free treatment and basic diagnostics at primary care centres regardless of insurance status, they do not cover other OOP costs (Jiang et al. 2024). The JKN, which covers formally employed individuals or those registered as poor, extends coverage to include hospitalization, additional diagnostics, and medicines to treat symptoms (Pisani et al. 2017, Agustina et al. 2019). Our findings suggest that insurance reduced financial hardship during the pandemic, potentially due to offering this broader protection. Finally, patients seeking services from public hospitals incurred higher OOP payments, which can be explained by the fact that public hospitals usually provide services for the more complicated cases of TB compared to the puskesmas (Winardi et al. 2022).

Our study revealed key factors contributing to financial challenges as well as patients' coping strategies during the pandemic. First, job loss due to lockdowns and subsequent disqualification from the JKN insurance were perceived as significant factors contributing to financial hardship. The loss of employer-sponsored health insurance during the COVID-19 pandemic was documented across a range of settings globally, including in high-income countries such as the USA (Geyman 2022). Our findings suggest that the pandemic may have exposed a weakness in tying health insurance to employment. Second, stigma contributed to increased OOP expenses during the pandemic, as some patients, fearing discrimination, opted to seek healthcare from distant or private providers, thereby incurring higher costs. Previous studies have shown that HIV/TB patients may forego subsidized or free public care in favour of more discreet, often costlier, private options due to fear of judgement, loss of social standing, or breach of confidentiality (Ogbonna et al. 2024, Clement et al. 2015, World Bank 2022, Alfaiate et al. 2023, Sukmaningrum et al. 2024). Several coping strategies were reported by participants in our study, including borrowing from relatives, relying on contributions from family and friends, and selling assets. Efforts like these have been reported in several other studies captured in a previous literature review (Rahman et al. 2022).

Our study findings hold important implications for policymakers developing and refining financial protection schemes during large-scale public health emergencies. Firstly, financial protection measures can be improved by targeting poorer households and considering contextual (e.g. location) and social factors (stigma) that increase the risk of higher OOP spending. Secondly, there may be an unmet need to expand coverage for TB and HIV patients to include additional OOP costs related to seeking treatment, such as transport

expenses. To address the burden of travel-related OOP costs, policymakers could explore several policy options. One approach would be to provide conditional travel subsidies or vouchers, tied to appointment attendance or treatment adherence (Guimarães et al. 2023). Local governments could also consider budget reallocations to support community-based care models or mobile clinics, which would reduce the need for long-distance travel (Barnabas et al. 2020). Furthermore, there is a need to ensure the continuity of health coverage for those who lose their employer-provided insurance due to job loss and to integrate antistigma strategies in universal health coverage efforts.

Several limitations should be considered when interpreting the results of this study. Firstly, bias in cost data and IDIs may have arisen because of the purposive nature of our sample (participants were included if their service was interrupted). Secondly, as our sampled patients were recruited in the facility, patients whose financial circumstances prevented them from seeking healthcare (i.e. those who forwent treatment) were not included in either the cost diaries or IDIs. This exclusion may have led to an underestimation of the CHS incidence. Thirdly, for practical reasons, we did not collect data on indirect costs (e.g. income loss due to illness or loss of productivity), which the WHO estimated in 2023 to account for approximately half (47%) of the total spending for TB patients in Indonesia (World Health Organization 2023c). The proportion of hospitalized patients in our dataset was <1%, which may also have led to an underestimation of CHS incidence, as hospitalization was found to be a major driver of healthcare spending (Fuady et al. 2018, McAllister et al. 2020). Finally, recall bias may have been an issue for those maintaining a diary, although the use of an aid memoire and fortnightly follow-up calls by the research team may have helped address this (Goossens et al. 2000, Wahid et al. 2024).

Conclusion

Additional financial protection is crucial for ensuring continued access to essential health services during large-scale public health crises. Our study found that households with patients suffering from HIV and TB experienced financial hardships during the pandemic, including catastrophic health costs, loss of income, and challenges with JKN coverage. The risk of incurring OOP costs was lower among those insured, yet higher among patients requiring secondary care and those whose facility was located in Yogyakarta, highlighting areas for targeted policies to reduce the financial burden on households.

These findings suggest that for policies to provide improved financial protection during public health crises, they should focus on poorer households, individuals facing job loss, and those whose medical conditions necessitate hospital care. Expanding protection to encompass travel costs can be achieved through measures such as demand-side incentives (e.g. conditional travel vouchers and cash transfers). We encourage further research to develop strategies for alleviating financial difficulties, particularly those arising from the pandemic. This will aid in preparing national healthcare systems and ensuring continued financial support for those affected.

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Supplementary data

Supplementary data is available at *Health Policy and Planning* online.

Author contributions

V.W., A.P., M.L., R.A.A., and H.T. conceptualized the study. S.N.S.N., Y.A.M., and S.D.W. contributed to data curation. N.F. conducted the statistical analysis. S.N.S.N, S.D.W, Y.A.M., and N.F. conducted qualitative analysis. S.N.S.N., Y.A.M., Q.C., I.W.C.S.D.P., A.P., H.T., M.L., V.W., and N.F. contributed to the interpretation of the results. N.F. wrote the original draft. All authors reviewed and approved the final manuscript. M.L. supervised the work.

Reflexivity statement

The co-authors of this paper are from diverse backgrounds in discipline, gender, and seniority levels. Seven authors are female (S.N.S.N., Y.W.S., L.P.L.W., S.D.W., A.P., Q.C., and V.W.). Nine co-authors are Indonesian (S.N.S.N., Y.W.S., Y.A.M., L.P.L.W., I.W.C.S.D.P., S.D.W., A.P., H.T., and R.A.A.). Six are early career researchers (N.F., S.N.S.N., Y.A.M., L.P.L.W., I.W.C.S.D.P., and S.D.W.). M.L. is a social scientist, and V.W. is a health economist. Both have extensive experience in health systems and economics research in Southeast Asia. A.P. is a health services researcher with 13 years of experience in TB control in Indonesia. This study is part of a collaborative research project between several Indonesian Universities, the University of South Wales, and the London School of Hygiene & Tropical Medicine.

Ethical approval

The study was approved by the ethics committees of Universitas Gadjah Mada Yogyakarta (KE/FK/1410/EC/2021), the London School of Hygiene & Tropical Medicine (22829), and UNSW Sydney (HC200989). All participants in the cost diaries and IDIs agreed to participate by signing a written consent form. The study was conducted in accordance with the Declaration of Helsinki.

Conflict of interest

None declared.

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Data availability

The data used in this study are not publicly available. However, anonymised data will be made available upon reasonable request to the corresponding author in accordance with the Indonesian regulation on data sharing.

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