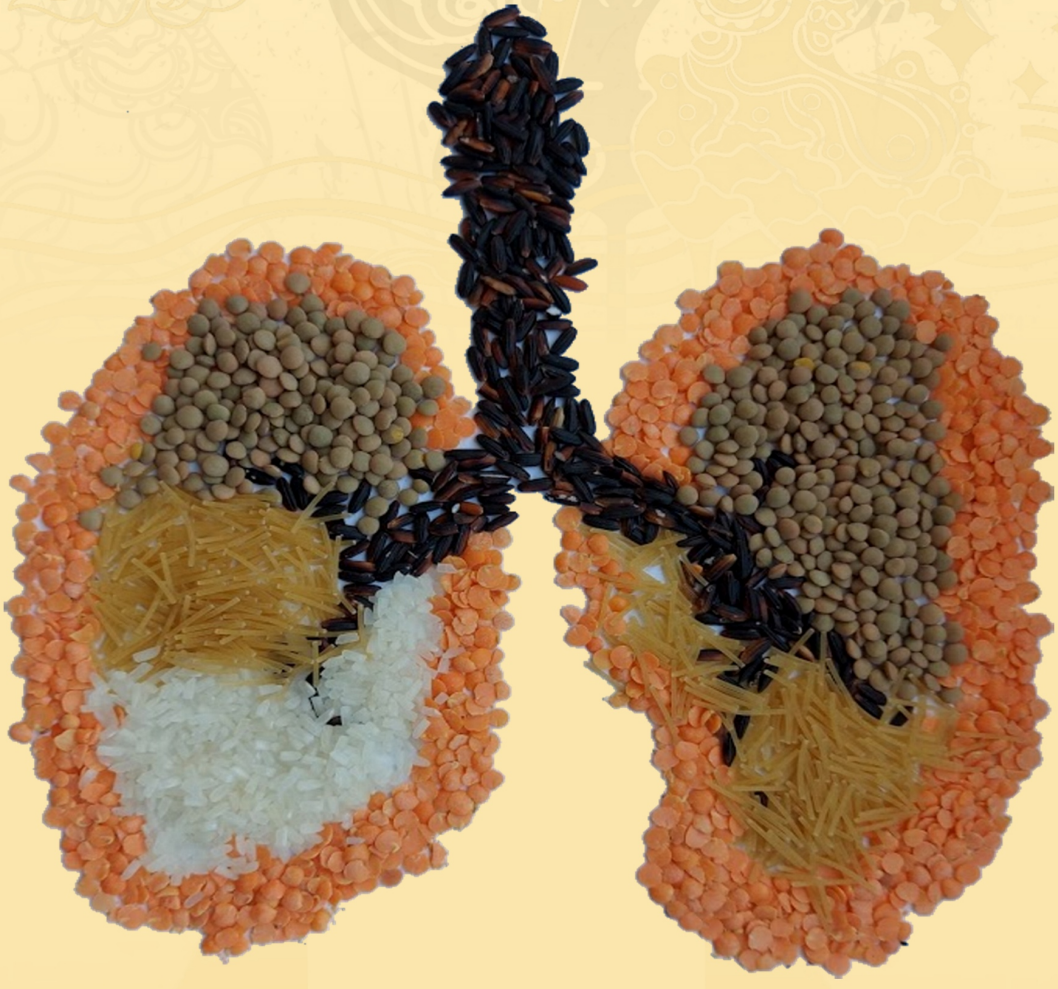
Tuberculosis-related Catastrophic Costs Since the Implementation of Universal Health Coverage in Indonesia



Ahmad Fuady

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Tuberculosis-related Catastrophic Costs Since the Implementation of Universal Health Coverage in Indonesia

Tbc-gerelateerde Catastrofale Kosten Sedert de Implementatie van Universele Ziektekostenverzekering in Indonesië

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Chapter 1

General introduction

Tuberculosis

Tuberculosis (TB) is an infectious disease with a very long history. It has been hypothesized that the origin of the genus Mycobacterium emerged during the *Jurassic* era, more than 150 million years ago.[1] In Ancient Greece, *phthisis* – a disease with symptoms and lung lesions similar to those of TB in modern medicine – was well known.[2] In the Middle Ages, people found that the disease also affected the cervical lymph nodes; it was called *scrofula*.[3] In thirteenth-century England and France, where it was believed that monarchs were endowed with supernatural power from God,[3] it was also believed that *scrofula* could be diagnosed and cured by the "royal touch" – a practice used by French kings and English kings and queens to heal their people. The illness was known as the *King's evil*, and the "royal touch" was used until 1712 in England and 1825 in France.[2]

During the industrial revolution, the disease spread widely in poor communities, due largely to malnutrition, bad working conditions, bad sanitation, and overcrowded, poorly ventilated housing.[1, 2] In the late 19th century, many physicians and researchers undertook experiments, including the sanatorium cure, which was introduced in Germany by Herman Brehmer, who stated in his doctoral dissertation that TB was a curable disease.[2] On March 24, 1882, Dr. Robert Koch successfully identified Mycobacterium tuberculosis as its cause.[4] After centuries of speculation, this significant event produced a new understanding of the disease. Eventually, this led to the development of a strategy that combined drug discovery, effective treatment, and socioeconomic development.

In the early 20th century, TB mortality rates in Europe, Japan, and North America declined rapidly.[5, 6] Due to this successful reduction in the incidence and mortality of TB, the disease was often regarded as a disease of the past. But in other parts of the world, particularly low and middle-income countries, the disease burden of TB was still high. In 1993, the World Health Organization (WHO) declared that TB was a global health emergency, and that national and global efforts to combat it should be intensified.[6]

Global TB epidemiology

In 2017, despite drug development and socioeconomic improvements, there were still an estimated 10 million incident cases of TB worldwide[7] – equivalent to 133 cases per 100 000 population. Most cases occurred in South-East Asia (44%) and in African regions (25%) (Figure 1). Some 87% of all estimated incident cases occurred in TB high-burden countries (HBCs), and were concentrated in eight countries: India (27%), China (9%), Indonesia (8%), Philippines (6%), Pakistan (5%), Nigeria (4%), Bangladesh (4%), and South Africa (3%).

Figure 1 Estimated TB incidence in 2017 for countries with at least 100 000 incident cases (Source: WHO, 2018)

Globally, progress has been made in reducing TB mortality. Between 2000 and 2016, the number of deaths due to TB fell by 24%, while the mortality rate due to TB (deaths per 100 000 people per year) fell by 37%.[6] However, TB among HIV-negative people is still the tenth most important cause of death worldwide (Figure 2). If estimates include TB-related deaths among people who are HIV positive, the number of deaths is even higher. Worldwide, an estimated 1.33 million TB patients died in 2017. Approximately 1.3 million of these deaths occurred among TB patients who were HIV negative, and 300 000 among people who were HIV positive. TB deaths were concentrated in the African and South-East Asian regions, which between them accounted for 82% of all TB-related deaths.[7, 8] In addition, of all single infectious agents, TB is the top cause of death, causing a larger number of deaths than HIV/AIDS.

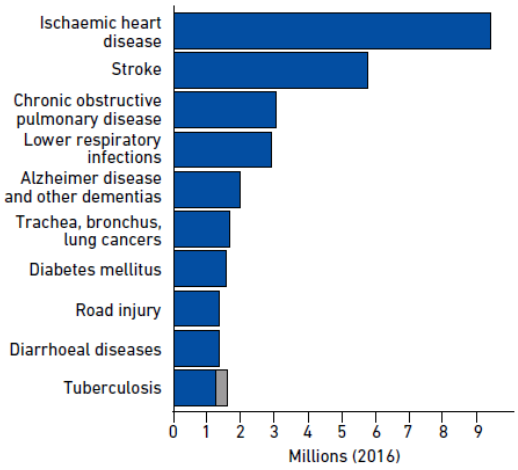

Figure 2 Top causes of death worldwide in 2016 (Source: WHO, 2018). With regard to tuberculosis, the blue bar indicates TB deaths among HIV-negative people, and the gray bar TB deaths among HIV-positive people.

Global TB control

These statistics show that vast national and global efforts are still required to eliminate TB. In a resolution issued in the World Health Assembly (WHA) in 1991, the World Health Organization (WHO) stressed the importance of combating TB, declaring that TB was a global health emergency.[6, 9] The resolution was supported by the introduction of an internationally recommended TB control strategy known as DOTS (Directly Observed Treatment Short-course),[10] whose key components included government commitment, case detection, standardized short-course chemotherapy with supervision and patient support, regular drug supply, and system monitoring and evaluation.

In 2000, the first Global Plan to Stop TB was launched by setting up actions to control TB over the 2001–2005 period. The strategy has been supported by initiatives such as the Amsterdam Declaration (2000), the Washington Commitment to Stop TB (2001), and the Stop TB Partners' Forum in Delhi (2004).[9] Global and national TB elimination programs were also engaged in the efforts to achieve the Millennium Development Goals (MDGs) target of "halving TB prevalence and TB mortality rates by 2015 compared with their levels in 1990".[9, 11]

The assessment of the MDGs' and Stop TB Strategy's targets indicated that, on a worldwide basis, the target were achieved. Global TB prevalence had declined by 42% compared with the level in 1990. In three WHO regions – the Americas, South-East

Asia, and the Western Pacific regions – and in nine HBCs, the decline rates were more than 50%.[11] The global TB mortality rate also declined by 47% compared the rate in 1990[12] while the overall number of TB deaths declined by 24% between 2000 and 2016.[6] The target of halving TB mortality was achieved in four WHO regions – the Americas, the Eastern Mediterranean, the South-East Asia, and the Western Pacific regions – and eleven HBCs.

However, the global target of eliminating TB still faces many challenges. Although the incidence of TB has declined over the years, the rate of decline has been slow: only 1.4-1.5% per year in the period 2000-2017,[6, 12] and 1.8% between 2016 and 2017.[7] There has also been an increase in TB drug resistance, not only in Rifampicin Resistant TB (RR-TB), in which the disease is resistant to rifampicin as the first-line drug, but also multidrug-resistant TB (MDR-TB), in which it is resistant both to rifampicin and to isoniazid. In 2017, the global incidence of MDR-TB and RR-TB concerned an estimated 558 000 cases,[7] most of them in China, India, and Russia. As experience in some Eastern European countries has shown, treatment success may be greatly reduced by the high prevalence of MDR-TB.[12]

The global response to these challenges were embodied the Sustainable Development Goals (SDGs) and the WHO's latest End TB Strategy. One of the targets of the SDGs is to "end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases, and [to] combat hepatitis, water-borne diseases, and other communicable diseases" by 2030.[13] In numerical terms, this target means that, relative to the rates in 2015, the TB incidence rate must be reduced by 80% and TB death rates by 90%. The WHO End TB Strategy, in parallel, has set targets to reduce the incidence by 90% and death rates by 95% by 2035. The End TB Strategy has a longer timeframe in which it ends in 2035 rather the SDG's timeframe which ends in 2030.[7, 14] These two targets are ambitious and need huge efforts by national and global policymakers.

TB in Indonesia

Indonesia is among the world's 30 high-burden TB countries. In 2018, the country had 845 000 new TB cases, which accounted for 8% of TB cases worldwide.[15] As its incidence of TB was 316 per 100 000 population, Indonesia is third highest in the

worldwide ranking, with a TB mortality rate of 40 per 100 000 population. These stark figures indicated that TB was still the top burden of diseases in Indonesia.

In the era of the MDGs (2000–2015), Indonesia had set two main indicators to monitor achievement of the MDG target related to TB control: increasing the detection of new smear-positive TB cases to 70%, and increasing the cure rate to 85% of such cases by the year 2000.[6, 9] Setting up the indicator of increasing new smear-positive TB case detection to 70% based on the fact that TB case detection in practice was not effective. There was a high proportion of detected smear-negative TB cases, which are more likely found by X-ray test rather than by sputum smear examination, and are also less contagious. In addition, there had been also a high number of undetected TB smear-positive cases. To achieve this indicator, the Indonesian National Tuberculosis Program (NTP) intensified the DOTS strategy – the internationally recommended strategy for TB control. In 2015, at the end of the MDGs era, Indonesia had achieved these two indicators (improving TB case detection and cure rate), but had failed to halve TB prevalence and mortality rates.[11, 16]

The achievement and the failure both indicated the complex situation of TB in Indonesia, which is characterized by three main problems. The first – a high number of undetected cases[7, 17] – results from the failure of healthcare providers to comply with the standard of TB diagnosis recommended in the national TB practice guidelines. This may be due to limited knowledge on the part of physicians, or to limited healthcare facilities – particularly laboratory facilities – for the sputum smear examination. One way and another, the high number of undetected cases leads to patient diagnostic delays, the spread of TB in the community, and potentially high costs for patients and their households.[17-19]

The second problem is a high number of cases that have been detected but not notified. This problem was captured by a national inventory study in 2017.[7, 17] Despite the achievement that 85% of TB cases had been detected in 2015, the estimated incidence – which was used to estimate the detection rate – had been generated from the data stored in the NTP information system (the Integrated Information System for Tuberculosis, or *Sistem Informasi Tuberkulosis Terpadu*, SITT). Only healthcare providers linked with NTP report to the SITT. While a substantial proportion of TB patients seek care from healthcare providers that are not linked to the NTP, many TB cases are not captured by the SITT.[7, 20] As a result, the TB cases detected in these health

facilities were not notified to the NTP. This in turn led to an underestimation of TB incidence, as it was based solely on the data in SITT, and also to a substantial overestimation of the case-detection rate.

The third problem is the high number of patients who are lost to follow up, i.e., as having missed TB treatment for more than two consecutive months. There are various reasons a patient may stop treatment: lack of knowledge, unawareness of the consequences of stopping TB treatment before completion, adverse effects of TB drugs, poor access to healthcare facilities, and high costs incurred during TB treatment.[19, 21]

TB care system in Indonesia

To reduce the TB burden, Indonesia's NTP operates under the auspices of the Ministry of Health.[22] As the body responsible for running the TB control program, the NTP coordinates directly with Provincial Health Offices (PHOs) and District Health Offices (DHOs) (Figure 3). The NTP has a sizeable primary care network, which consists mostly of publicly funded primary health centers (PHCs) or *Puskesmas*. There are two main types of PHC or *Puskesmas* in Indonesia: *Puskesmas,* which operate at sub-district level, and auxiliary *Puskesmas* (*Puskesmas Pembantu*, *Pustu*), which operate at village level. The NTP delivers free TB drugs to *Puskesmas* through the DHOs. Most *Puskesmas* have large facilities, including laboratories, so that they can run TB diagnostic tests for suspected TB patients. This type of *Puskesmas* functions as a "referral microscopic center" for diagnosis. *Puskesmas* or *Pustu* with very limited facilities have to refer suspected TB patients to referral *Puskesmas* for diagnosis and to obtain free TB drugs. In addition, the NTP also has a network of public hospitals and clinics under the authority of ministries, such as the prison clinics under the Ministry of Law and Human Rights.

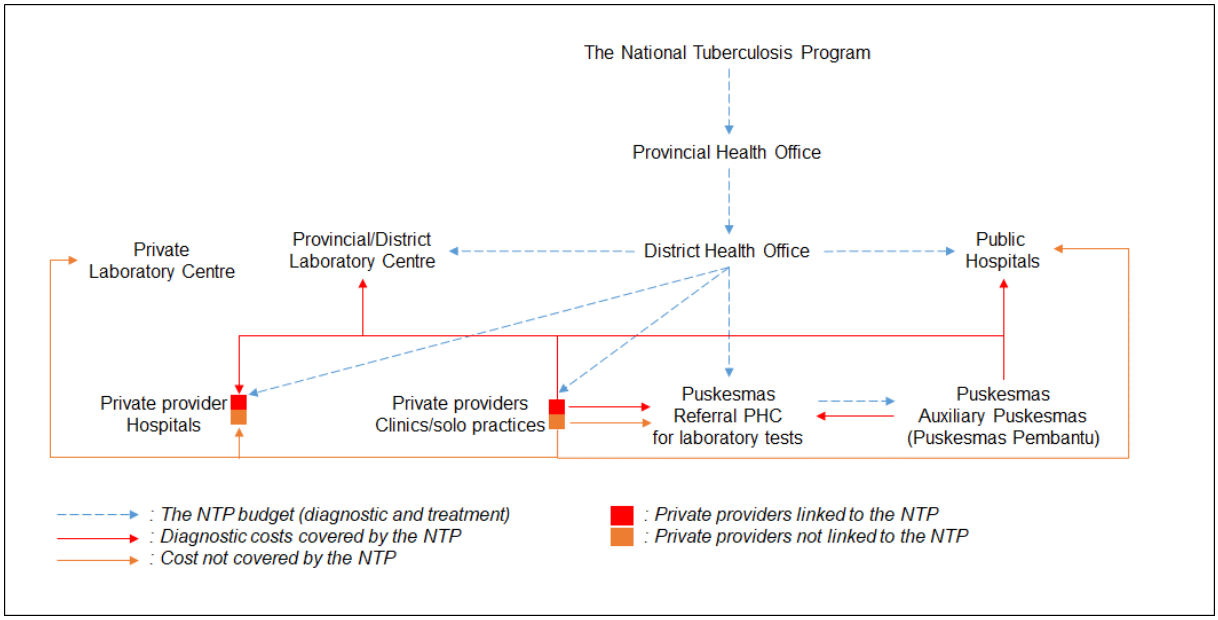

Figure 3 Referral for diagnostic tests under the network of Indonesia's national tuberculosis program

Private clinics and private hospitals can be linked to the NTP through mutual agreements with either a *Puskesmas* or a DHO. To be eligible for this, they must meet various requirements: physicians in the clinics or hospitals must have completed a DOTS training, and the clinics and hospitals must agree to comply with the national TB guidelines and report TB case findings and management to the NTP. If clinics linked with the NTP have a laboratory for TB diagnostic tests, they can provide these tests free of charge. In other cases, they should refer suspected TB patients to a referral *Puskesmas*, a hospital, or a provincial/district laboratory center. If the suspected patient is TB-positive, a private clinic can, according to its mutual agreements, submit a request for free TB drugs to either a *Puskesmas* or the DHO. The private clinic is then required to submit a TB case-management report. Private hospitals linked to the NTP receive free TB drugs from the DHO, to which they should then report on the TB case management.

Until 2014, however, only about 11 000 of the 70 000 (16%) private healthcare providers were linked to the NTP network.[17, 23] According to the TB National Prevalence Survey (2014), almost 75% of suspected TB patients first sought care with private providers.[17] As a result, the providers were unable to provide free access to TB diagnostic tests and TB drugs.

Universal health coverage in Indonesia

In 2014, Indonesia started a national health insurance program (*Jaminan Kesehatan Nasional*, JKN) to achieve universal health coverage (UHC). It is run by a Social Security Agency for Health (*Badan Penyelenggara Jaminan Sosial – Kesehatan*, BPJS-K) that was set up for the purpose. In its first five years of operation, the program's population coverage increased from 46% to 75%.[23] The government covers the monthly contribution fee for poor households, which, using data from the National Statistical Agency, was established on the basis of a household's ability to fulfill its basic food and non-food needs.[24] Non-poor households pay a contribution fee that varies according to the type of BPJS-K membership.

The BPJS-K has an extensive network of public and private providers, where patients who are the beneficiaries of the national health insurance can access free essential health services. All public healthcare providers are automatically linked to the BPJS-K. In 2018, there were also approximately 11 500 private providers in the BPJS-K network.[25] The numbers of private healthcare providers linked to BPJS-K will continue to grow.

After the implementation of UHC, TB care service is delivered through two separated system (Figure 4). First, as mentioned above, the NTP coordinates TB care system from the direction of the Ministry of Health (national level) to the PHOs, the DHOs, and its network of providers (*Puskesmas*, clinics, laboratories, and hospitals). The budget of providing TB care services is arranged entirely by the government. By this system, suspected TB patients could access free TB diagnostic tests only at health providers that were linked to the NTP. All free TB drug is provided only though the NTP network. Second, the BPJS-K also allows free TB diagnostic tests at private providers that are linked to BPJS-K, regardless of the providers' status in the NTP network. Private providers who do not have a laboratory can refer suspected TB patients for diagnostic tests to a BPJS-linked facility.[26]

However, not all private providers who are linked to BPJS-K also have direct links to the NTP network. If the private providers are part of the NTP network, they can receive free TB drugs and deliver the drugs to the TB patient. Private providers who are not linked to the NTP cannot provide free TB drugs, and should refer TB patients to an NTP-linked health provider. With this new approach and with a strongly increasing number of private providers that are linked to BPJS-K, it is assumed that UHC in Indonesia will improve its TB control program and reduce patients' direct medical costs.

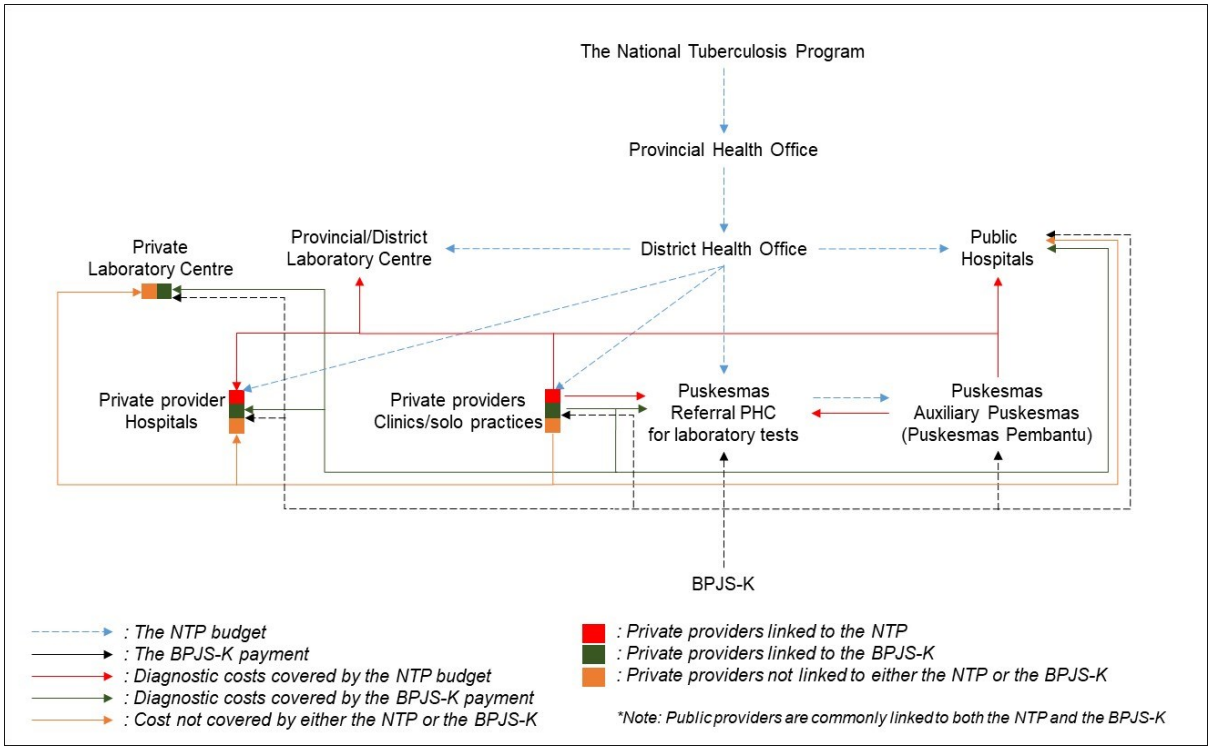

Figure 4 The latest guidelines for diagnostic tests referral after the implementation of UHC.

Still, the BPJS-K is not linked directly to the Indonesian NTP. If health providers are not part of the NTP network, they may not have attended the DOTS training and may not have managed suspected TB patients and diagnosed TB patients according to the NTP's guidelines. At present, however, the BPJS-K provides no specific requirements or guidelines on managing TB cases according to the NTP guideline, DOTS, or the International Standard of Tuberculosis Care (ISTC).

The overall picture shows that the provision of care for TB in Indonesia is fragmented across the BPJS-K and the NTP systems. While the basic assumption is that the national health insurance program can improve TB control program and reduce patients' direct medical costs, there is insufficient evidence on whether the UHC can mitigate the high costs incurred by TB patients and TB-affected households. It is also important to assess whether it has still been possible for patients to incur costs due to TB since UHC was implemented, and, if so, for what cost item and how much the costs are incurred.

The financial burden due to TB

Accessing TB-related services is often costly. Overall, without sufficient insurance or program coverage, patients often incur high direct medical costs, for, among others,

diagnostic procedures, TB drugs, and consultation fees.[27] Patients may face high costs, starting in the pre-diagnostic phase, i.e., the period between the occurrence of the first symptoms or signs and TB diagnosis. Costs during this phase can be high due to diagnostic or health-system delays, which are defined as the time that elapses between a patient's first healthcare facility visit and the date of starting of TB treatment.[28-30] Since patients may seek care with multiple health providers before obtaining the definitive diagnosis of TB, the length of such delays can vary. [27, 31]

When a patient is diagnosed with TB, he or she needs to undergo a long TB treatment without any interruption.[32] Those who are newly infected (Category 1) should complete a six-month course of treatment – two months in the intensive phase and four months in the continuation phase. Those who have become re-infected (Category 2) should complete eight months of treatment – three months in the intensive phase and five months in the continuation phase.

Even though patients receive free TB drugs and medical consultations, they still incur high costs for direct non-medical costs, such as transportation and food during their visits to the healthcare facility.[33, 34] Patients in Indonesia need to visit their healthcare provider approximately 2-4 times a month during the intensive phase and 1-2 times a month during the continuation phase. The number of visits is higher for those undergoing Category 2 treatment. If a patient needs one or more family member to accompany them during the healthcare visits, these costs may increase.

As well as direct medical and non-medical costs, TB patients or their guardians may, due to their frequent visits to the healthcare provider, also face losses of income, productivity, and time.[27, 34, 35] Patients may also experience job loss, typically for reasons such as the high frequency of healthcare visits, their worse health, or stigmatization in the workplace.

Such economic consequences can be catastrophic, particularly for poor households. On the one hand, accessing TB-related services may further reduce their financial capacity, eventually casting them into a poverty trap.[36, 37] On the other hand, catastrophic costs may hamper their further access to healthcare.

Catastrophic costs due to TB

In 2015, the WHO End TB Strategy set a target for the first milestone (2020): reducing to zero percent the percentage of TB-affected households that faced catastrophic costs.[38] This definition of "catastrophic costs" is different from that of another, similar-sounding indicator, "catastrophic expenditures," which is commonly used to measure progress towards UHC.[39, 40] While catastrophic costs are a UHC indicator that focuses on direct medical costs only, the End TB indicator captures the total economic burden of TB, and therefore incorporates indirect costs into its calculation of catastrophic costs.[40-42]

Measuring the economic impact of TB thus incorporates three types of cost. The first, direct medical costs, represent actual spending on medical services, such as administration and consultation fees, and costs for laboratory tests, treatment, and hospitalization. The second, direct non-medical costs, are often incurred during healthcare visits, and consist of indirect costs or income loss. They are associated with healthcare utilization, such as transportation costs and food costs. The third, indirect costs, are any loss of income that result from accessing TB-related services.

The WHO recommends two approaches to measuring catastrophic costs and whether or not the zero-percent target of households facing such costs has actually been achieved. The first approach defines catastrophic costs as the total costs incurred by TB-affected households that exceed a specific threshold – such as 20% – of the household's annual income. The second approach defines catastrophic TB-related costs as the share of TB-affected households that experience dissaving by taking a loan or selling property or livestock to deal with TB-related costs.[41]

In Indonesia, no evidence has yet been produced on measurements of the incidence of catastrophic costs due to TB according to the new approach introduced by the End TB Strategy in 2015, i.e., measuring all direct and indirect costs. Neither is there currently any evidence on the extent to which households still face catastrophic costs since UHC was implemented through the JKN program. As we approach the 2020 milestone of the End TB Strategy – i.e., a zero percent incidence of catastrophic costs – it is crucial to assess the current situation in Indonesia. It is essential to assess whether Indonesia's universal health insurance program is sufficient to protect TB patients from catastrophic costs, or whether they need additional protection against the economic impacts of TB.

The aim, research questions, and outline of the thesis

In the context of UHC in Indonesia, this thesis aims to provide an evidence base on the following: 1.) the household-level economic impact of TB, 2.) the relationship between catastrophic costs and TB treatment outcomes, and 3.) the social-protection improvements required to further reduce TB-related catastrophic costs. In more specific terms, this thesis intended addresses the research questions below.

1. What is the economic impact of TB faced by TB-affected households?
2. What is the contribution of private health care providers to this economic impact of TB?
3. Do catastrophic costs affect patients' TB treatment adherence and treatment outcome?
4. What is the potential effect on the incidence of catastrophic costs of further social protection measures beyond UHC?

The thesis consists of seven chapters. Chapter 2 describes the development and adaptation of the tool developed by the WHO to measure TB-related costs in the context of Indonesia since the implementation of the UHC. In answer to the first research question, Chapters 3 and 4 quantify the economic impact of TB, including the incidence of TB-related catastrophic costs. Chapter 4 explores the contribution of private healthcare providers to the economic impact due to TB. Chapter 5 describes whether or not catastrophic costs, and at which percentage of costs related to annual household income, affect TB treatment outcome and TB treatment adherence. After presenting a simulation of eight financial support scenarios for reducing the incidence of catastrophic costs, Chapter 6 explores the patients' remaining needs for additional financial or social protection. The general discussion in Chapter 7 summarizes and discusses our findings, and makes recommendations for further research and policy development regarding the TB-control program and social protection.

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Chapter 2

Adaptation of the Tool to Estimate Patient Costs for tuberculosis-affected households in Bahasa Indonesia

Ahmad Fuady[1,2], Tanja A.J. Houweling[1], Muchtaruddin Mansyur[2], Jan Hendrik Richardus[1]

[1]Department of Public Health, Erasmus MC, University Medical Center Rotterdam, The Netherlands. [2]Department of Community Medicine, Faculty of Medicine, Universitas Indonesia, Indonesia.

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Abstract

Aim:

To adapt the Tool to Estimate Patient Costs which measures total costs and catastrophic total costs for tuberculosis-affected household to the Indonesian context.

Methods:

The Tool was adapted using best-practice guidelines. On the basis of pre-testing performed in a previous study (referred to as Phase 1 Study), we refined the adaptation process by comparing it with the generic tool introduced by the WHO. We also held an expert committee review and did pre-testing by interviewing 30 TB patients. After pre-testing and before finalization, the Tool was provided with complete explanation sheets.

Results:

Seventy-two major changes were made during the adaptation process including changing choices to match the Indonesian context, refining the flow of questions, deleting questions, changing some wordings, and restoring original questions that had been changed in Phase 1 Study. Participants indicated that most questions were clear and easy to understand. To solve recall difficulties, we made some adaptations to obtain data that might be missing, such as tracking data to a patient's medical records, making a proxy of costs, and guiding interviewers to ask for a specific value when participants were uncertain about the estimated market value of property they had sold.

Conclusions:

The adapted Tool to Estimate Patients' Costs in Bahasa Indonesia is comprehensive, ready for use in future studies on TB-related costs catastrophic costs, and suitable for monitoring progress towards the target of the End TB Strategy.

Introduction

Indonesia is achieving slow progress in its struggle to eliminate tuberculosis (TB). With the world's second-highest TB incidence worldwide,[1] it urgently requires improvements and innovations beyond the strategies currently being implemented throughout the country. While training of healthcare workers is essential, it is also important to note that access to healthcare often brings financial hardship to TB patients. The most vulnerable are those living in poor families, who must deal not only with medical costs, but also with non-medical costs, such as travel and supplementation costs, which can drain up to half of their annual income.[2,3] All these costs are compounded by potential income loss.[4]

Challenges in eliminating TB therefore go beyond clinical management, and are often related to socioeconomic problems. These problems can increase delay in TB diagnosis and treatment, and plunge patients into a more severe state of TB illness and a higher risk of treatment failure and MDR-TB development.[2–4] This, in turn, will lead to more complicated cases with substantial implications for clinical management. Clinicians should therefore consider the financial problems faced by TB patients and their affected families during consultations.

Many patients, because of embarrassment, prefer firstly seek care to private providers rather than to public health facilities, regardless their financial capacity. Assessing patients' financial capability will help clinicians to decide whether they can prescribe additional diagnostic tests, such as X-ray, and branded drugs that may be unaffordable for patients. Otherwise, they should refer patients to public health facilities linked to National Tuberculosis Program (NTP) that provide free-of-charge laboratory examination and TB drugs. During TB treatment, clinicians should also assess whether patients can afford transportation costs before deciding the number of visits per month. Assessing all of these issues is important to increase patients' adherence to the TB diagnostic procedures and treatment, as well as TB treatment success.

Understanding the complexity of TB burden, the End TB Strategy acknowledges the importance of these socio-economic determinants in its target that, by 2020, no TB-affected family should face catastrophic spending due to TB.[5–7] In countries such as Indonesia, it is very important that progress towards this target is monitored properly. One fundamental step in monitoring progress is preparing a validated tool for measuring total patient costs and catastrophic total costs. The World Health Organization (WHO)

recommends using a version of the generic questionnaire "The Tool to Estimate Patient Costs"[7,8] (henceforth referred to as the Generic Tool) that has been adapted to the local cultural context in order to interpret findings correctly.[9,10] Before Indonesia's implementation of universal health coverage (UHC) in 2014, Van den Hof *et al.* adapted the Generic Tool for use in Indonesia; it was pretested in 2013. For the sake of convenience, we refer to this study as the Phase 1 Study.[11,12]

However, due partly to the implementation of UHC, various answer categories in the Phase 1 Tool (such as those relating to health insurance and healthcare facilities), no longer matched the new situation. Also, as pretesting in the Phase 1 Study involved only five multi-drug-resistant (MDR) TB patients, a larger sample size was needed to perfect the adaptation.

To monitor progress towards the target of eliminating catastrophic spending on TB in Indonesia, the present study aimed to further adapt the questionnaire resulted from the Phase 1 Study.

Methods

Study design

The adaptation of the Tool consisted of two phases. The first phase had been conducted separately by van den Hof *et al.*[12] for a previous Indonesian study (the Phase 1 Study) in 2013. Our study (referred to henceforth as the Phase 2 Study) comprised the second phase of adapting the Generic Tool. Our study had a cross-sectional design and was conducted in 2016. In line with existing guidelines,[13,14] the whole process of adaptation consisted of seven steps. While the Phase 1 Study went through all the steps from I to VII, our Phase 2 Study re-ran steps V to VII, i.e. production of the definitive Bahasa Indonesia version of the Tool. (Figure 1)

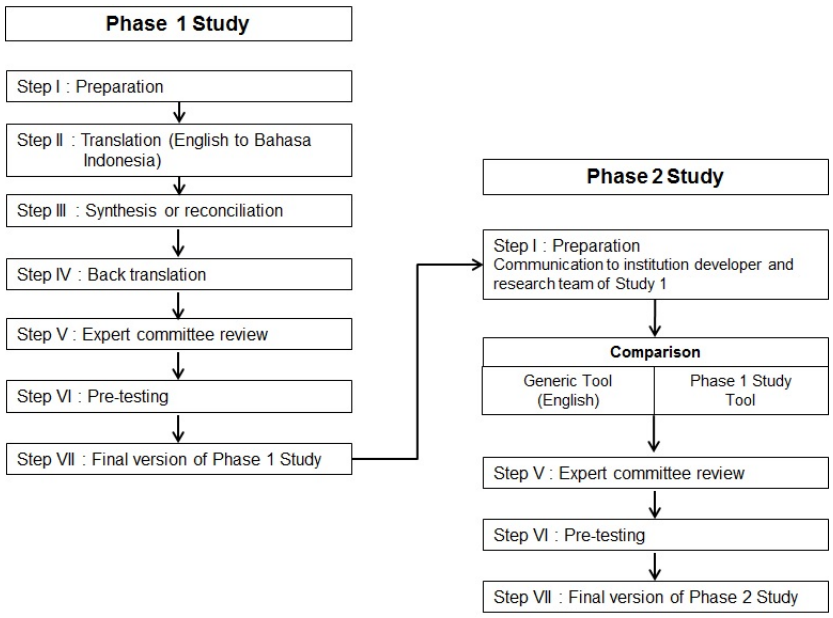

Figure 1 Study design: adaptation of the Tool

Study population

We interviewed 30 TB patients who had undergone at least one month of TB treatment in two sub-district Primary Health Centres (PHCs, *Puskesmas*), East Jakarta, which were Puskesmas Cakung and Puskesmas Jatinegara. We tracked patients registered on the TB patient list and chose patients who met the inclusion criteria consecutively from the most recent starting date of treatment. In Puskesmas Cakung, we invited TB and MDR-TB patients to come to PHC, and interviewed patient coming to the PHC consecutively. In three consecutive days, we interviewed 18 patients. In Puskesmas Jatinegara, we phoned patients to make an appointment, and visited them at home for an interview until reaching 12 TB and MDR-TB patients. If a patient could not be interviewed because he/she was unable to communicate or was not available at the time of interview, we asked his/her caregiver (termed "drug observer") to participate in the study. This brought the total number of interviewees to 30.

Phase 1 Study

The principal investigator of the Phase 1 Study was a researcher from the KNCV Tuberculosis Foundation in the Netherlands, where the Generic Tool was originally developed. The study was prepared in Indonesia together with local researchers, one of whom was appointed to prepare for the forward translation into Bahasa Indonesia.

Various questions, such as those on insurance types, types of healthcare facility, and reimbursement schemes, were adapted to the local context. To check for interpretation errors, the questionnaire was back-translated, and then pre-tested on five MDR-TB patients at Persahabatan Hospital, in Jakarta.[11] Its clarity for patients and interviewers was tested. After this pre-testing, further adaptations were made, culminating in the final version of the Phase 1 Study Tool. We obtained this final version, and compared it with the English Generic Tool.

Phase 2 Study

In our Phase 2 Study, we further refined this adapted version of the Tool to the current Indonesian context. Rather than going through all the steps again, we used the Phase 1 Study Tool as a starting point for adaptation and began the process at step V (expert committee review). Before doing so, we contacted the researchers of the Phase 1 Study by telephone and email, and asked their permission to use their version for further adaptation.

Expert committee review

The objective of the expert committee review (step V) was to check the content of the Tool once again. For the purpose, we invited key persons to discuss the Phase 1 Tool. As well as local researchers, this meeting included the following external experts: a pulmonologist specialized in infection, a staff member from the Sub-Directorate for Tuberculosis at the Ministry of Health, Republic of Indonesia; and a psychometrics expert.

Before the meeting, the principal investigator – an Indonesian national – made a brief report in which he commented on questions and choices in the Generic Tool that remained uncertain or could be misinterpreted. The committee then compared the Generic Tool and the Phase 1 Study Tool, focusing on various sections in the WHO protocol that would need to be adapted to the local context. The adaptations included provider type, the TB care-delivery model, socio-demographic variables, net revenue from labour-related activities, health insurance and social protection; and household assets. In addition to revising these sections, the committee also checked the entire

Generic Tool and suggested some changes to the Phase 1 Study Tool. This stage resulted in a penultimate version of the Indonesian translation of the tool.

Pre-testing

In a one-day training before the pre-testing, we trained six medical students to interview 30 TB and MDR-TB patients or his/her caregiver (if the patient was unable or unavailable for interview) in two sub-district PHCs of East Jakarta. After each respondent had been interviewed, interviewers reported any difficulties they had encountered with regard to completing the tool or to the respondents' understanding of the questions. The researchers also discussed the findings, made changes, and formulated the final version of the Tool in Bahasa Indonesia.

Final version

After pretesting and refinement, we developed the final version of the Tool. We also provided comprehensive explanation sheets to guide the interview.

Ethical aspects

Pre-testing the Tool was part of our main study, which assessed catastrophic total costs among TB-affected households. We had obtained ethical approval from the Ethical Committee of the Faculty of Medicine, Universitas Indonesia and Cipto Mangunkusumo Hospital (No. 416/UN2.F1/ETIK/VI/2016) before the study. Before the interview, we provided oral and written explanation to respondents and required them to sign informed consent. We ensured the confidentiality of all information collected from the interview.

Results

In total, 72 major changes were made during the adaptation process from the Generic Tool to the final version of Study 2 (see **Annex A**). The adaptations consisted of the following: reformulating questions and choices to reflect the current Indonesian

context; re-structuring the ordering of several questions; deleting certain questions from the Generic Tool; and later restoring questions which had previously been deleted in the Phase 1 Study.

Phase 1 Study involved 60 changes relative to the Generic Tool. As well as the addition of two question sets under new sub-topics (moving costs and adverse effect costs), these changes included changing question sets into table form, adding seven questions and one sub-question, altering five answer choices and two wordings, and deleting three question sets (sub-topics) and 33 questions.

The most important change made in the Phase 1 Study was the overall flow of the Tool. In the Generic Tool, the questions are grouped on the basis of the types of cost. This required respondents to recall the costs they had incurred back and forth between the pre-diagnostic, diagnostic, and treatment phases. To facilitate the flow of interview, the Phase 1 Study had re-arranged the flow to match the time sequence. Other prominent changes involved redesigning some questions into table form, which made it easier for the interviewers to ask them and thereby to complete the Tool.

During the expert review meeting in Phase 2 Study, we changed the answer choices relating to provider type from “Health Post (*Pos Kesehatan*)”, “PHC (*Puskesmas*), and “district hospital (RSUD)” to “PHC (*Puskesmas*)”, “private clinic”, “public hospital”, “private hospital”, and “other”. With reference to the TB delivery model, we changed the term “DOT” (Directly Observed Treatment), which respondents may not know, to “visit to take TB drugs” to make it easier for participants to understand the questions. In the section with socio-demographic questions, we changed categories relating to income payments (paid regularly, uncertain, paid in kind, not paid, and others). We also changed a question from “currently formally employed” to “formally employed before being diagnosed”, and followed with the question “Did you have to change or quit your employment after being diagnosed with TB?”. We restored a question “how many people regularly sleep in your household”, and modified it to “how many family members live in your household?”.

As UHC had been implemented in Indonesia since the Phase 1 study, the insurance system had changed. Using the abbreviation BPJS to indicate the national health-insurance agency (*Badan Penyelenggara Jaminan Sosial*, BPJS), we adapted the types of insurance to government-paid BPJS, self-paid BPJS, and private insurance. No changes were made to questions in the revenue section. However, we made changes in

the costs section, including the type of supplement taken ("drinks" to "milk"); the frequency of taking supplementation (from "per month" to "per week"); and the coping section (by changing the order of the questions on the amount of money gained from selling property). We also changed some wordings to make it easier for participants to understand questions, for example changing the term "smear" to "*Basil Tahan Asam* (BTA)", and "*pengembalian asuransi*" to "*reimbursement asuransi*".

We retained 38 questions that were the result of adaptations made in the Phase 1 Study. We also restored 12 original questions from the Generic Tool that had been changed, and five original questions that had been deleted in the Phase 1 Tool. The restored questions included "date of first diagnostic examination", "date of starting treatment", "where did you seek treatment?", "what symptoms did you experience?", and "why didn't you go to a public facility?". We also deleted three questions and three answer choices that had been added in the Phase 1 Study.

Pre-testing

Seventy-four percent of the participants received the Category I therapy regimen; only 7% took MDR therapy. The majority (63%) underwent TB treatment in the continuation phase. (Table 1)

Table 1 Participants characteristics

Characteristics	N	%	Characteristics	N	%
Participant			Type of TB		
TB patients	27	90	Pulmonary, smear +	22	73
Drug observers	3	10	Pulmonary, smear -	7	23
Sex			Pulmonary, smear unknown	1	4
Male	15	50	Therapy regimen		
Female	15	50	Cat I	22	73
Age category, *years old*			Cat II	6	20
18-30	5	17	MDR	2	7
31-40	6	20	Therapy phase		
41-50	5	17	Intensive phase	11	37
>50	14	46	Continuation phase	19	63
Educational level					
Low	10	33			
Intermediate	20	67			

The respondents indicated that the majority of questions were clear and easy to understand. However, they had problems answering some others. Most respondents forgot the date of their first TB examination (63%) and the date they started treatment (57%). Neither did they know their HIV status (53%). We therefore added explanatory notes for interviewers in the interview guidance. Instead of asking these data to participants, interviewers should track the data in the patients' medical records. Respondents had difficulty to estimate transportation costs if they used their own vehicle. To deal with that, we guided interviewers to ask transportation-related costs such as parking or toll fees, but not fuel costs.

Many participants received bills from healthcare facilities that stated total amounts without any itemization. They had difficulty to distinguish between administration, laboratory, X-ray and drug costs. In such cases, we allowed interviewers to enter the total amount under administration costs. We deleted sub-questions under hospitalization costs and left only one question on total hospitalization costs since participants could not detail hospital item costs. If a TB patient had sold property and did not know the estimated market value, we added a question "Did the price conform to the estimated market value?" and trained interviewers to ask the specific price when participants were uncertain about the market value of property they had sold.

Annex B contains the final version of the questionnaire resulting from our Phase 2 study, together with the explanatory notes (**Annex C**).

Discussion

The Tool was successfully adapted to the current Indonesian context. It is now ready for use in similar studies on TB cost measurement and for monitoring progress towards the End TB Strategy target. Under the terms of the strategy, the government should monitor this target until 2035. Monitoring TB related costs can help identify determinants of TB treatment outcomes, and reduce the risk to treatment failure, severe adverse outcome, and further spread of TB, MDR-TB, or even XDR-TB because of socio-economic problems.[2,4,15–17]

In our view, the adapted Tool is suitable for the purpose: it is more comprehensive than previous versions and is fully consistent with the situation that has pertained in

Indonesia since the implementation of UHC. The Tool can measure not only total costs, but – as recommended by the WHO – also catastrophic total costs.[7]

As well as the refinements made to the Phase 1 version of the Tool, the strengths of this study include the relatively large number of respondents recruited, their wide age-range, and the balance between the sexes. A limitation is the fact that we only interviewed participants who were undergoing TB and MDR-TB treatment in PHCs. Thereby we excluded those who underwent TB treatment in other types of health facility or who dropped out of TB treatment. However, this limitation is acknowledged in the WHO protocol, which excludes TB patients treated in facilities that are not linked to the national tuberculosis program. This means that the adapted Tool is now the most appropriate questionnaire for measuring catastrophic total costs.

The translation that followed from the Phase 1 Study was acceptable and easily understood, and there was no need for re-translation from English to Bahasa Indonesia. However, difficulties were encountered when seeking appropriate translations for terms such "DOT", "dispensary", and "mission hospital" that have no specific equivalent in Bahasa Indonesia. Another potential source of misunderstanding was how participants define "primary income earner" or "*pencari nafkah*", which may lead to confusion between "*pencari nafkah"* (primary income earner/breadwinner) and "*kepala keluarga"* (head of family). We therefore inserted an explanation of "primary income earner" as the highest earners who actually spent their earnings on financing the household.

In rural or remote areas of Indonesia where Bahasa Indonesia is not used in daily life, future studies will need to further adapt the Tool to the cultural context and local language. It is imperative that all question items are explained clearly in the local languages.

The adaptation of the tool also provides useful insights for clinical practice. Instead of merely focusing on clinical complaints of TB patients, clinicians should also take socioeconomic problems into account, including the availability of health insurance, traveling costs to visit the health facility, and potential income or job loss faced by the patient and their families. Assessing patients' financial capacity will help clinicians to decide on appropriate prescription, including any additional supplements needed. Clinicians may also refer patients to existing social protection programs, e.g., national

health insurance or national employee insurance, if patients are uninsured, or refer them to primary health centers that provide TB diagnostic and treatment freely.

Conclusion

Our adapted version of the Tool to Estimate Patient Costs proved to be acceptable for use in Indonesia. Together with its explanations, it is easily understood by interviewers and interviewees. It is ready for use in future studies on tuberculosis-related cost estimation and catastrophic spending measurement.

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Chapter 3

Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of universal health coverage

Ahmad Fuady[1,2], Tanja A.J. Houweling[1], Muchtaruddin Mansyur[2], Jan Hendrik Richardus[1]

[1]Department of Public Health, Erasmus MC, University Medical Center Rotterdam, The Netherlands. [2]Department of Community Medicine, Faculty of Medicine, Universitas Indonesia, Indonesia.

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Abstract

Background:
As well as imposing an economic burden on affected households, the high costs related to tuberculosis (TB) can create access and adherence barriers. This highlights the particular urgency of achieving one of the End TB Strategy's targets: that no TB-affected households have to face catastrophic costs by 2020. In Indonesia, as elsewhere, there is also an emerging need to provide social protection by implementing universal health coverage (UHC). We therefore assessed the incidence of catastrophic total costs due to TB, and their determinants since the implementation of UHC.

Methods:
We interviewed adult TB and multidrug-resistant TB (MDR-TB) patients in urban, suburban and rural areas of Indonesia who had been treated for at least one month or had finished treatment no more than one month earlier. Following the WHO recommendation, we assessed the incidence of catastrophic total costs due to TB. We also analyzed the sensitivity of incidence relative to several thresholds, and measured differences between poor and non-poor households in the incidence of catastrophic costs. Generalized linear mixed-model analysis was used to identify determinants of the catastrophic total costs.

Results:
We analyzed 282 TB and 64 MDR-TB patients. For TB-related services, the median (interquartile range) of total costs incurred by households was USD 133 (55-576); for MDR-TB-related services, it was USD 2804 (1008-4325). The incidence of catastrophic total costs in all TB-affected households was 36% (43% in poor households and 25% in non-poor households). For MDR-TB-affected households, the incidence was 83% (83% and 83%). In TB-affected households, the determinants of catastrophic total costs were poor households (adjusted odds ratio [a*OR*] = 3.7, 95% confidence interval [*CI*]: 1.7-7.8); being a breadwinner (a*OR*= 2.9,95%*CI*: 1.3-6.6); job loss (a*OR*= 21.2; 95%*CI*: 8.3-53.9); and previous TB treatment (a*OR*= 2.9; 95%*CI*: 1.4-6.1). In MDR-TB-affected households, having an income-earning job before diagnosis was the only determinant of catastrophic total costs (a*OR*= 8.7; 95%*CI*: 1.8-41.7).

Conclusions:
Despite the implementation of UHC, TB-affected households still risk catastrophic total costs and further impoverishment. As well as ensuring access to healthcare, a cost-mitigation policy and additional financial protection should be provided to protect the poor and relieve income losses.

Background

The estimated 1.4 million deaths to tuberculosis (TB) in 2015 exemplify the persisting burden of TB. With a global incidence that declines by only 2% annually worldwide, slow progress is being made towards the target for eliminating the disease by 2035.[1,2] These stark figures show that global action should be taken to adjust strategies and to combine initiatives such as promoting clinical adherence and providing socio-economic support.[3,4]

Although TB patients in most high TB-burden countries have free access to anti-TB drugs, they often incur high costs for travel and food, and suffer income losses that can amount to over half of annual household income.[5,6] Such financial hardship creates an adherence barrier to diagnostic procedures and treatment, resulting in poor outcomes and increasing the risk of transmission in the community.[5-8] Accessing TB-related services also has economic consequences. The job or income losses experienced by TB patients, especially those in the productive age group, can reduce the financial capacity of their households and cast them into the poverty trap.[9-11]

To address the socio-economic determinants and financial impact of TB, the WHO End TB Strategy acknowledges the need for social protection by setting a clear first milestone that no TB-affected families should face catastrophic TB-related costs after 2020.[1,2] This target complements the Sustainable Development Goal (SDG) of achieving universal health coverage (UHC) through the provision of more affordable and high-quality healthcare services.[3,12]

Indonesia started its UHC program in 2014 by offering national public insurance and by engaging more private providers in the network managed by the Social Security Agency (*Badan Penyelenggara Jaminan Sosial*, BPJS), the Ministry of Health and the Ministry of Social Affairs. It is assumed that direct medical costs, which are costs incurred for diagnostic tests, treatment, and follow-up tests, will be reduced by the national insurance scheme, which covers all medical costs in primary to tertiary care, including TB-related services.[13] Due to Indonesians people's strong preference for seeking care with private providers, the involvement of more private providers in the BPJS network is also expected to have an impact by reducing medical expenses which were reportedly three times higher than those charged by public providers,[14] and by reducing the number of people who develop TB but are not diagnosed or cannot access

TB care services that conform with International Standard of Tuberculosis Care (ISTC).[9]

Accessing healthcare services is time-consuming and costly.[9,10,15-17] The Indonesian National TB Program (NTP) has attempted to provide support in the form of food/nutritional supplementation and travel vouchers, for example, in addition to diagnostic examination and drug costs coverage. However, the policy has changed and the support has been restricted or even ended. It leaves direct non-medical costs including travel and food/nutritional supplement costs uncovered and can lead to catastrophic health expenditure (CHE). As TB and multidrug-resistant TB (MDR-TB) require a long period of treatment, and also worsen the health status, TB patients also suffer from job or income losses that aggravate the risk of catastrophic costs and barriers to treatment adherence.

The WHO has introduced a new term "Catastrophic total costs" as the TB-specific indicator that differs in essence from CHE. CHE is defined as the share of the population spending more than a given threshold and focuses on direct cash spending or out-of-pocket (OOP) payments made by household to improve or restore health of household members. The TB-specific indicator of "catastrophic total costs" incorporates direct medical costs, direct non-medical costs, and overall indirect costs, and also helps to capture the economic burden specific for TB.[18,19] It is therefore crucial for TB elimination programs to identify the main cost drivers, monitor financial hardship, and establish which further health and social policy measures should be taken.[18] For this reason, we aimed not only to measure the incidence of catastrophic total costs caused by TB and the sensitivity of the incidence relative to a range of specific thresholds, but also to assess differences between poor and non-poor households in terms of the incidence of catastrophic total costs and to identify the determinants of catastrophic total costs since Indonesia's implementation of UHC.

Methods

Study design

From July to September 2016, stratified clustered sampling was used to enroll TB patients in an urban district (Jakarta), a suburban district (Depok) and a rural district

(Tasikmalaya). Per district, we randomly selected 6-8 primary health centers (PHCs) linked with the NTP. Until reaching our predetermined sample size, we enrolled all the consecutive TB patients who attended these PHCs and who also met our inclusion criteria: they were aged 18 years or above, had undergone the adult diagnostic procedure, had been treated for at least one month or had finished treatment no more than a month previously, and had signed informed consent. Extra-pulmonary TB cases were excluded. Assuming a power of 0.80, a 1:1:1 ratio of urban to suburban to rural districts, and that the incidence of TB-related catastrophic total costs in each district was 20%, 25%, and 30%, we collected a minimum of 90 patients in each district.

MDR-TB patients were enrolled at Persahabatan Hospital, an MDR-TB referral hospital in Jakarta. We selected those adult MDR-TB patients who came to the hospital consecutively, had undergone MDR-TB treatment in the hospital for at least one month, had recorded a diagnostic result as MDR-TB, either by GenXpert or sputum culture; and had signed the informed consent form.

Cost measurement

Ten medical students and public health graduates were recruited and trained as interviewers. Using the adapted Bahasa Indonesia version of the Tool to Estimate Patient Costs, they then interviewed patients and/or their drug observer, i.e., a family member who was selected as the patient's direct-observation-of-treatment supporter.[20-22] Retrospectively, each respondent reported all types of cost related to the TB care services they had incurred during the pre-diagnostic, diagnostic, and treatment phases. (Table 1)

Pre-diagnostic and diagnostic costs

The pre-diagnostic and diagnostic costs were the sum of all the direct and indirect costs incurred for pre-diagnostic and diagnostic visits. The direct costs included all OOP payments incurred after any reimbursement for medical fees and all non-medical expenditures made by patients or their guardian (i.e., a family member who accompanied them during visits). Indirect costs consisted of the income loss reported by patients and guardians.

Table 1 Definition of costs and income used in this study

Variables	Definition	Direct costs	Indirect costs
Pre-diagnostic and diagnostic costs	All types of cost incurred during the period between the onset of symptoms and diagnosis with TB in public or private healthcare facilities, at a pharmacy, or by a practitioner of alternative medicine.	*Medical*: Costs of consultation, administration, laboratory tests, X-ray examinations, and drugs. *Non-medical*: Costs of food and travel for patient and/or guardian.	Patient's and guardian's income losses.
Treatment costs	All types of cost incurred after being diagnosed and treated for TB, includes the costs of hospitalization and adverse events.	*Medical*: Costs of administration, evaluation (laboratory test, X-ray examination, or others), hospitalization, and adverse events. *Non-medical*: Costs of food and travel (for patient and/or guardian), and food supplements.	Patient's and guardian's income losses.

Treatment costs

The costs of anti-TB drugs are covered by the NTP. We calculated the administration or registration fee, food and travel costs that were typical for each visit. To estimate the costs per month, we then multiplied these cost items by the number of visits per month. Any travel vouchers given to patients were included as a deduction of travel costs. We also summed treatment evaluation costs according to the number of evaluation tests conducted. We estimated patient's income losses on the basis of income changes reported after diagnosis with TB. To avoid underestimates for people such as taxibike drivers who continued to earn uncertain monthly incomes from informal jobs, we also estimated time-loss value. To calculate this time-loss value, we used the following formula: round trip in minutes for a typical visit × patient's income loss per minute × the number of visits per month.[5]

We interviewed some patients in the intensive treatment phase and others in the continuation treatment phase. For patients interviewed during the intensive phase, we obtained the reported costs of the intensive phase from the patient and estimated the costs in the continuation phase on the basis of the data of other patients in other PHCs within a similar district. For patients interviewed during the continuation phase, we obtained reported costs from the patient in both the intensive and continuation phases, then extrapolated the reported costs to obtain the total costs of both phases. To estimate the entire treatment costs, we extrapolated the monthly costs according to the internationally defined durations of the intensive and continuation phases: (a) two months (for the intensive phase) and four months (for the continuation phase) of new TB treatment (Category I); (b) three and five months for re-treatment (Category II), and (c) eight and twelve months for MDR-TB treatment.[5,23,24]

We summed other direct medical costs, e.g. hospitalization and any adverse event costs, that were uncovered by health insurance. We also calculated monthly nutritional/food supplement costs incurred by patients, such as vitamins, fruit, milk, meat, or other supplements consumed as a result of TB treatment.

To measure income loss, we established the household income earned through the incomes of patients and other family members, through government aid, and through other income, before and after the patients had been diagnosed with TB. A household earning below USD 1.9 per capita per day was classified as a poor household.[25] As many Indonesians live in extended families that may have more than one income earner per household, we defined a patient as breadwinner if his/her income was at least 10% higher than that of any other family member.[26,27] All costs and incomes were converted to US dollars using the average exchange rate calculated by the World Bank for 2015 (USD 1 = IDR 13389.41).[28]

Catastrophic total costs

The WHO protocol takes two approaches to measuring the percentage of patients experiencing catastrophic total costs. The first is based on total costs, and defines catastrophic total costs as total costs (direct and indirect costs) incurred by household that exceed 20% of the household's annual income. The second approach defines catastrophic total costs as the share of TB patients who experience dissaving by taking

a loan or selling property or livestock to deal with costs related to TB[18]. In this study, we applied the first approach. Total costs due to TB were defined as the sum of the OOPs incurred for medical diagnosis and treatment (OOPM), OOPs for non-medical expenditures related to the use of TB care services (OOPNM), and patients' and guardians' reported income losses or time losses valuations (IN), net of any reimbursement and welfare payments. The denominator was reported annual household income in the year before diagnosis with TB.[18]

$$I_{NTP}^{TB} = \frac{1}{n_{NTP}^{TB}} \sum_{i=1}^{n_{NTP}^{TB}} 1\left(\sum_{j=1}^{n_i} \frac{OOPM_j^{TB,h} + OOPNM_j^{TB,h} + IN_j^{TB,h}}{y_i^h} > \tau^{TB} \right)$$

As well as measuring the incidence of catastrophic total costs, referred to here as the headcount (H), we established the sensitivity of this headcount (i.e. incidence) relative to thresholds of 5%, 10%, 15%, 20%, and 25% as used in other previous studies.[10,11] For each threshold, we also calculated mean gap indicators (G) and mean positive gap (MPG). The G indicates the average amount by which payments, as a proportion of household income, exceed the threshold. The MPG is equal to G/H, and helps to identify how excessive the total costs are by indicating the excess expenditure per household that experiences catastrophic total costs.[7,11,31,32]

To analyze the different pictures provided by the catastrophic total cost approach and the CHE approach, we compared the H's, G's, and MPGs per threshold between these two approaches.[29,30] Per threshold, we also analyzed differences between poor and non-poor households in the H's, G's, and MPGs of catastrophic total costs.

Fourteen patient variables were examined as potential determinants of catastrophic total costs: (1) district (urban, suburban, rural), (2) household income (poor and non-poor), (3) sex, (4) age group, (5) educational level (primary school as "low," junior school and senior high school as "intermediate"; and college and university as "high"), (6) being a family breadwinner, (7) having had an income-earning job before diagnosis, (8) having insurance before being diagnosed, (9) having had previous TB treatment, (10) HIV status, (11) hospitalization for the current TB treatment, (12) first contact with the facility after having symptoms of TB, (13) taking supplementation, and (14) experiencing adverse effects.

Data analysis

To ensure data quality, we used Microsoft Excel 2010 and EpiInfo version 7 (CDC, Atlanta) to double-enter and to check the data. Abnormally distributed data were displayed as median (inter-quartile range [IQR, q25-q75]), while categorical variables were shown as numbers and proportions (%). The Mann-Whitney test was used to compare all types of the cost incurred for access TB-related services between poor and non-poor households.

We used random effects to adjust for our cluster sampling design (19 PHCs), and used the generalized linear mixed model to examine determinants of the incidence with which TB-affected households faced catastrophic total costs. For MDR-TB cases, we used binary logistic regression to examine the determinants of catastrophic total costs. In the univariate analysis, we estimated the significance (*P*), the crude odds ratios (c*OR*s), and their 95% confidence intervals (*CI*s). To identify the best model and estimate the significances, adjusted *OR*s (a*OR*s) and the 95% *CI*s of the determinants, we included all variables with a $P<0.25$ in the univariate analysis in a multivariable analysis.

Ethical issues

Before the interview, all respondents received written and oral explanations of the study and signed an informed-consent form. Ethical clearance for this study was provided by the Ethical Committee at the Faculty of Medicine of Universitas Indonesia–Cipto Mangunkusumo Hospital, Jakarta, Indonesia (No. 416/UN2.F1/ETIK/VI/2016) and the Ethical Committee at Persahabatan Hospital, Jakarta, Indonesia (No. DL.01.03/II.3/3817/2016).

Results

Patients characteristics

As eight (3%) of the 354 eligible TB and MDR-TB patients did not report their household income, we analyzed the data for 346 patients (282 TB and 64 MDR-TB patients). (Table 2) Most patients were of working age, had an intermediate educational background, and lived in a poor household. Thirty-two percent of the TB patients with

an income-earning job had lost their job after diagnosis, against 69% of the MDR-TB patients. Less than one-third (23%) of the TB patients in the urban study area did not have health insurance, compared with 59% in the rural study area. Most patients had smear-positive TB and were divided equally according to the phase of treatment.

Most TB patients first sought care at primary health center. Our results also show that a high proportion of TB patients went first to a private provider; even in rural areas, this figure was 46%. Investigation of the reasons for not choosing a public provider showed that the distance to the public facility was a prominent issue, as were personal preference and familiarity with a specific private facility. (See **Annex D**)

Table 2 Patient characteristics

Characteristics	TB (%)								MDR-TB (%)	
	Total		Urban		Suburban		Rural			
Sex	*n=282*		*n=95*		*n=90*		*n=97*		*n=64*	
Male	155	(55)	51	(54)	52	(58)	52	(54)	31	(48)
Female	127	(45)	44	(46)	38	(42)	45	(46)	33	(52)
Age in years										
18-40	137	(49)	45	(47)	47	(52)	45	(46)	34	(53)
41-64	123	(44)	44	(46)	38	(42)	41	(42)	29	(45)
>64	22	(8)	6	(6)	5	(6)	11	(11)	1	(2)
Educational level										
Low	99	(35)	25	(26)	18	(20)	56	(58)	12	(19)
Intermediate	172	(61)	67	(71)	65	(72)	40	(41)	42	(65)
High	11	(4)	3	(3)	7	(8)	1	(1)	10	(16)
Household income										
Poor	175	(62)	46	(48)	45	(50)	84	(87)	23	(36)
Non-poor	107	(38)	49	(52)	45	(50)	13	(13)	41	(64)
Breadwinner										
Patient	124	(44)	48	(51)	38	(42)	38	(39)	25	(39)
Not patient	158	(56)	47	(49)	52	(58)	59	(61)	39	(61)
Income-earning job										
Yes	201	(71)	73	(77)	61	(68)	67	(69)	49	(77)
No	81	(29)	22	(23)	29	(32)	30	(31)	15	(23)
Job loss										
Job loss	64	(23)	17	(18)	18	(20)	29	(30)	34	(53)
No job loss	218	(77)	78	(82)	72	(80)	68	(70)	30	(47)
Having health insurance										
Yes	176	(62)	73	(77)	63	(70)	40	(41)	56	(87)
No	106	(38)	22	(23)	27	(30)	57	(59)	8	(13)
Insurance type	*n=176*		*n=73*		*n=63*		*n=40*		*n=56*	
BPJS, (paid by government[a])	119	(68)	52	(71)	33	(52)	34	(85)	24	(43)
BPJS, (self-paid[b])	53	(30)	19	(26)	28	(44)	6	(15)	32	(57)
Private insurance	4	(2)	2	(3)	2	(3)	0	(0)	0	(0)

Characteristics	TB (%)								MDR-TB (%)	
	Total		Urban		Suburban		Rural			
Monthly income	*n=201*		*n=73*		*n=61*		*n=67*		*n=49*	
Paid regularly	90	(45)	32	(44)	39	(64)	19	(28)	34	(69)
Uncertain	105	(52)	37	(51)	20	(33)	48	(72)	13	(27)
Others	6	(3)	4	(5)	2	(3)	0	(0)	2	(4)
	n=282		*n=95*		*n=90*		*n=97*		*n=64*	
Type of TB										
Pulmonary, smear +	186	(66)	70	(74)	62	(69)	54	(56)	64	(100)
Pulmonary, smear -	80	(28)	23	(24)	24	(27)	33	(34)	0	(0)
Pulmonary, smear unknown	16	(6)	2	(2)	4	(4)	10	(10)	0	(0)
Therapy phase										
Intensive phase	134	(48)	38	(40)	51	(57)	45	(46)	37	(58)
Continuation phase	148	(52)	57	(60)	39	(43)	52	(54)	27	(42)
HIV status										
Positive	6	(2)	5	(5)	1	(1)	0	(0)	0	(0)
Negative	92	(33)	51	(54)	17	(19)	24	(25)	32	(50)
Not tested/unknown	184	(65)	39	(41)	72	(80)	73	(75)	32	(50)
Hospitalization										
Yes	39	(14)	11	(12)	13	(14)	15	(16)	34	(53)
No	243	(86)	84	(88)	77	(86)	82	(84)	30	(47)
Previous TB treatment										
Yes	58	(21)	29	(31)	20	(22)	9	(9)	56	(87)
No	224	(79)	66	(69)	70	(78)	88	(91)	8	(13)
Completed previous TB treatment	*n=58*		*n=29*		*n=20*		*n=8*		*n=56*	
Yes	35	(61)	19	(65)	10	(50)	6	(75)	34	(61)
No	22	(39)	10	(35)	10	(50)	2	(25)	22	(39)
First contact										
Primary health center	127	(45)	51	(54)	40	(44)	36	(37)	29	(45)
Private clinic	94	(33)	26	(27)	26	(29)	42	(43)	2	(3)
Public hospital	32	(11)	11	(12)	10	(11)	11	(11)	25	(39)
Private hospital	20	(7)	4	(4)	13	(14)	3	(3)	8	(13)
Other facility	9	(3)	3	(3)	1	(1)	5	(5)	0	(0)

[a]Their national public insurance (BPJS) premiums were paid by the government; [b]They paid national public insurance (BPJS) premium out of their pocket. TB-related total costs

The median (IQR) of total costs was USD 133 in the TB group (55-576) and USD 2804 in the MDR-TB group (1008-4325). (Table 3)

Table 3 Costs of pre-diagnosis, diagnosis, and treatment of TB stratified by income at household level;median (IQR) in USD

Costs	TB			*P*	MDR-TB			*P*
	Total	Poor	Non-Poor		Total	Poor	Non-Poor	
Pre-diagnostic and diagnostic								
Direct costs	11 (3-21)	12 (4-22)	10 (2-21)	0.857	21 (7-47)	15 (5-35)	28 (7-67)	0.164
Indirect costs	1 (0-7)	1 (0-7)	0 (0-4)	0.136	4 (0-16)	1 (0-8)	5 (0-19)	0.141
Patient's income loss	0 (0-0)	0 (0-2)	0 (0-0)	0.089	0 (0-0)	0 (0-0)	0 (0-2)	0.428
Guardian's income loss	0 (0-0)	0 (0-0)	0 (0-0)	0.393	0 (0-0)	0 (0-0)	0 (0-0)	0.650
Total	13 (5-30)	15 (5-29)	12 (3-31)	0.75	27 (13-62)	20 (11-35)	32 (14-85)	0.049
Treatment								
Direct medical costs	0 (0-6)	2 (0-6)	0 (0-3)	0.851	15 (0-78)	9 (0-60)	17 (0-116)	0.328
Administration costs	0 (0-2)	0 (0-3)	0 (0-2)	0.426	0 (0-0)	0 (0-0)	0 (0-0)	0.454
Treatment evaluation costs	0 (0-0)	0 (0-0)	0 (0-0)	0.104	0 (0-0)	0 (0-0)	0 (0-0)	0.188
Hospitalization costs	0 (0-0)	0 (0-0)	0 (0-0)	0.748	8 (0-68)	0 (0-60)	15 (0-78)	0.499
Adverse effect costs	0 (0-0)	0 (0-0)	0 (0-0)	0.739	0 (0-0)	0 (0-0)	0 (0-0)	0.869
Direct non-medical costs	33 (8-97)	29 (9-90)	40 (8-117)	0.666	856 (430-1427)	941 (430-1255)	807 (430-1546)	0.690
Travel costs	7 (1-17)	9 (0-21)	4 (1-10)	0.004	403 (108-807)	403 (54-807)	403 (108-807)	0.457
Food costs	0 (0-5)	0 (0-6)	0 (0-4)	0.66	269 (0-459)	215 (0-403)	269 (0-538)	0.442
Food supplement costs	13 (0-67)	7 (0-54)	20 (0-90)	0.641	179 (4-347)	179 (90-448)	179 (0-291)	0.416
Indirect costs	8 (0-448)	11 (0-358)	4 (0-602)	0.236	1344 (2-2577)	269 (0-1882)	1792 (202-2913)	0.009
Patient's income loss	2 (0-448)	2 (0-358)	1 (0-602)	0.143	1344 (2-2577)	269 (0-1613)	1792 (2-2689)	0.015
Guardian's income loss	0 (0-0)	0 (0-0)	0 (0-0)	0.38	0 (0-0)	0 (0-0)	0 (0-0)	0.465
Total	117 (33-545)	108 (33-451)	135 (32-784)	0.352	2760 (989-4309)	1244 (448-3352)	3485 (1851-4638)	0.012
Total costs	133 (55-576)	132 (58-492)	138 (45-792)	0.277	2804 (1008-4325)	1268 (461-3363)	3506 (1914-4799)	0.011

The treatment costs amounted to 88% of median total costs for TB patients and 98% for MDR-TB patients. (Figure 1) Despite the low medians of indirect costs and patients' income loss, our results show that once patients lost their jobs, they lost a lot of their income. Among those who lost their jobs, average income loss amounted to 80% of total costs. Instead, the median annual income of TB and MDR-TB patients (USD 1344 and USD 2241) were much lower than the Indonesian GDP per capita in 2015 (USD 3834).

The differences in total costs between poor and non-poor TB patients were not statistically significant. However, in non-poor households affected by MDR-TB, the total costs were higher than in poor households, due mainly to higher income losses.

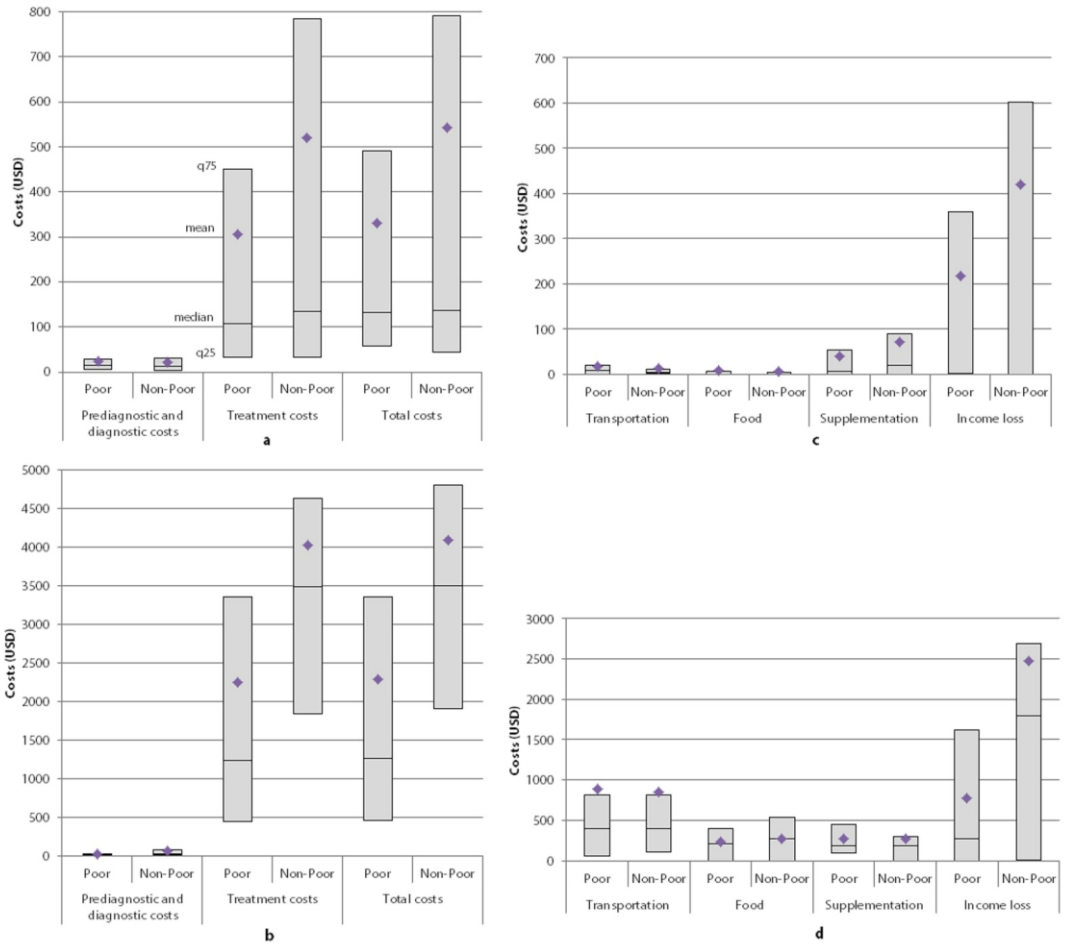

Figure 1 Costs incurred for TB-related services.
Pre-diagnostic and diagnostic costs, treatment costs and total costs between poor and non-poor patients in (a) TB groups and (b) MDR-TB groups; and costs incurred during treatment in (c) TB and (d) MDR-TB affected households. Means are indicated by blue rhombs, medians by a horizontal line, q25 by the bottom horizontal line of each box, and q75 by the top horizontal line of each box.

Catastrophic total costs

At the 20% threshold, the incidence, i.e. headcount, of catastrophic total costs was 36% for TB and 83% for MDR-TB; this was similar to the respective incidences of CHE at the 10% threshold (22% and 84%). (**Table 4**) However, the catastrophic total costs approach consistently showed higher mean gaps (G's) both for TB (10% vs. 4%) and MDR-TB (79% vs. 68%) than the CHE approach did.

Table 4 The headcounts of catastrophic costs due to TB and the sensitivity of these headcounts

Catastrophic costs	TB					MDR-TB				
	5%	10%	15%	20%	25%	5%	10%	15%	20%	25%
Catastrophic total costs[a]										
Headcount (%)		50	43	36	31		94	88	83	80
Mean gap (%)		14	12	10	8		88	83	79	75
Mean positive gap (%)		28	27	27	26		93	95	95	94
Catastrophic health expenditure[a]										
Headcount (%)	42	22	16	12		94	84	69	61	
Mean gap (%)	6	4	3	2		72	68	64	60	
Mean positive gap (%)	14	18	19	17		77	81	93	98	

[a]*Catastrophic total costs approach incorporates all type of costs, i.e. direct medical costs, direct non-medical costs, and overall indirect costs, while the CHE approach focuses only on direct cash spending or OOP payments made by household.*

There was an inverse association between catastrophic total costs and household income. Although their median total costs were not significantly different, poor TB-affected households, which had lower incomes, had higher headcounts than non-poor households (43% vs. 25%, P= 0.006 when using the threshold of 20%). (Table 5) The differences in incidence of catastrophic total costs between poor and non-poor households were also statistically significant with the thresholds of 10% (P=0.014), 15% (P=0.006), and 25% (P=0.009). For MDR-TB, the incidence of catastrophic total costs was similar for poor and non-poor households, irrespective of the threshold used. At the same time, the G's indicated that poor households suffered more than non-poor households (138% *vs.* 45% when using threshold of 20%). As the MPGs indicated, the gap was greater in poor households that faced catastrophic total costs (167%).

Table 5 Differences between poor and non-poor households in catastrophic total costs

Catastrophic total costs	TB				MDR-TB			
	10%	15%	20%	25%	10%	15%	20%	25%
Headcount								
Poor (%)	57	50	43	37	96	87	83	78
Non-poor (%)	39	32	25	22	93	88	83	81
Total (%)	50	43	36	31	94	88	83	80
P	0.014	0.006	0.006	0.009	0.111	0.117	0.115	0.121
Mean gap								
Poor (%)	18	15	13	11	147	142	138	134
Non-poor (%)	8	6	5	3	54	50	45	41
Total (%)	14	12	10	8	88	83	79	75
Mean positive gap								
Poor (%)	32	30	30	30	154	164	167	171
Non-poor (%)	19	19	18	16	58	56	55	51
Total (%)	28	27	27	26	93	95	95	94

Determinants of catastrophic total costs

With regard to catastrophic total costs among TB-affected households, there were four determinants: poor household (adjusted odds ratio [a*OR*] = 3.7; 95% confidence interval [*CI*]: 1.7-7.8; *P*=0.001); breadwinners (a*OR*= 2.9; 95%*CI*:1.3-6.6; *P*=0.010); job loss (a*OR*= 21.2; 95%*CI*: 8.3-53.9; *P*<0.001); and previous TB treatment (a*OR*= 2.9; 95%*CI*:1.4-6.1; *P*=0.006). (Table 6) Not being covered by health insurance was not a determinant of catastrophic total costs in either TB-affected or MDR-TB-affected households.

Table 6 Determinants of catastrophic total costs in TB cases

Determinants	Catastrophic total costs				*P*	cOR (95%CI)	*P*	aOR (95%CI)
	Yes	%	No	%				
Household income								
Poor	75	43	100	57	0.006	2.20 (1.26-3.86)	0.001	3.68 (1.74-7.78)
Non-poor	27	25	80	75		1.00		1.00
District								
Urban	35	37	60	63		1.00		
Sub-urban	22	24	68	76	0.125	0.54 (0.25-1.19)		
Rural	45	46	52	54	0.317	1.47 (0.69-3.16)		
Sex								
Male	57	37	98	63	0.710	1.10 (0.66-1.82)		
Female	45	35	82	65		1.00		
Age, years old								
18-40	49	36	88	64		1.00		
41-64	44	36	79	64	0.977	0.99 (0.59-2.67)		
>64	9	41	13	59	0.816	1.12 (0.43-2.90)		

Determinants	Catastrophic total costs				*P*	cOR (95%CI)	*P*	aOR (95%CI)
	Yes	%	No	%				
Educational level								
Low	41	41	58	59		1.00		
Intermediate	58	34	114	66	0.355	0.78 (0.45-1.33)		
High	3	27	8	73	0.479	0.60 (0.14-2.51)		
Breadwinner								
Patient	65	52	59	48	<0.001	3.60 (2.16-6.00)	0.010	2.92 (1.29-6.60)
Not patient	37	23	121	77		1.00		1.00
Income-earning job								
Yes	90	45	111	55	<0.001	4.66 (2.38-9.14)	0.881	1.08 (0.40-2.92)
No	12	15	69	85		1.00		1.00
Job loss								
Job loss	51	80	13	20	<0.001	14.07 (6.84-28.93)	<0.001	21.17 (8.31-53.90)
No job loss	51	23	167	77		1.00		1.00
Health insurance								
No	43	41	63	59	0.390	1.26 (0.74-2.15)		
Yes	59	34	117	66		1.00		
HIV status								
Negative	44	48	48	52		1.00		
Positive	0	0	6	100	0.953	0.00 (0.00-~)		
Not tested/unknown	58	32	126	68	0.863	0.46 (0.26-0.82)		
Previous TB treatment								
Yes	31	53	27	47	0.001	2.93 (1.56-5.48)	0.006	2.86 (1.35-6.05)
No	71	32	153	68		1.00		1.00
First contact with facility								
Private facility	46	37	77	63	0.622	1.14 (0.68-1.89)		
Public facility	56	35	103	65		1.00		
Hospitalization								
Yes	15	38	24	62	0.685	1.16 (0.56-2.38)		
No	87	36	156	64		1.00		
Food supplement								
Yes	65	34	126	66	0.370	0.78 (0.5-1.3)		
No	37	41	54	59		1.00		
Adverse effect								
Yes	53	43	71	57	0.029	1.77 (1.06-2.95)	0.089	1.77 (0.92-3.40)
No	49	31	109	69		1.00		1.00

c***OR***, crude Odds Ratio; a***OR***, adjusted Odds Ratio

With regard to MDR-TB-affected households, the multivariable analysis showed that the only determinant of catastrophic total costs in these households was having had an income-earning job before diagnosis (a*OR*= 8.7; 95%*CI*: 1.8-41.7; *P*=0.007). (Table 7)

Table 7 Determinants of catastrophic total costs in MDR-TB cases

Determinants	Catastrophic total costs				*P*	cOR (95% CI)	*P*	aOR (95%CI)
	Yes	%	No	%				
Household income								
Poor	19	83	4	17	0.974	0.98 (0.25-3.88)		
Non-poor	34	83	7	17		1.00		
Sex								
Male	27	87	4	13	0.383	1.82 (0.48-6.95)		
Female	26	79	7	21		1.00		
Age in years								
18-40	28	82	6	18		1.00		
>40	25	83	5	17	0.917	1.07 (0.29-3.95)		
Educational level								
Low	9	75	3	25		1.00		
Intermediate	35	83	7	17	0.515	1.67 (0.36-7.76)		
High	9	90	1	10	0.378	3.00 (0.26-34.58)		
Breadwinner								
Patient	21	84	4	16	0.840	1.15 (0.30-4.41)		
Not patient	32	82	7	18		1.00		
Income-earning job								
Yes	44	90	5	10	0.012	5.87 (1.47-23.47)	0.007	8.68 (1.81-41.70)
No	9	60	6	40		1.00		1.00
Job loss								
Job loss	34	100	0	0		1.00		
No job loss	19	63	11	37	0.998	0.00 (0.00-~)		
Health insurance								
Yes	46	82	10	18		1.00		
No	7	87	1	13	0.709	1.52 (0.17-13.79)		
HIV status								
HIV negative	28	87	4	13		1.00		
HIV not tested/unknown	25	78	7	22	0.331	0.51 (0.13-2.01)		
Previous TB treatment								
Yes	47	84	9	16	0.534	1.75 (0.29-2.01)		
No	6	75	2	25		1.00		
First contact facility								
Private facility	10	100	0	0	0.266	8.66 (0.19-403.74)		
Public facility	43	80	11	20		1.00		
Hospitalization								
Yes	30	88	4	12	0.235	2.27 (0.58-8.91)	0.090	3.92 (0.81-19.01)
No	23	77	7	23		1.00		1.00
Food supplement								
Yes	41	84	8	16	0.741	1.28 (0.29-5.77)		
No	12	80	3	20		1.00		
Adverse effect								

Determinants	Catastrophic total costs				*P*	cOR (95% CI)	*P*	aOR (95%CI)
	Yes	%	No	%				
Yes	38	86	6	14	0.270	0.47 (0.13-1.79)		
No	15	75	5	25		1.00		

c***OR***, crude Odds Ratio; a***OR***, adjusted Odds Ratio

Discussion

Despite the implementation of UHC in Indonesia, the country still has a high incidence of catastrophic total costs due to TB, particularly among patients who live in poor households and those who lose their jobs due to TB. In general, the greatest contribution to total costs was made by travel and food/nutritional supplementation costs. However, losing both job and income after diagnosis was also a critical point: once patients had lost their jobs, income loss became the main driver of total costs. These findings emphasize the importance not only of providing travel and nutritional supports but also social protection for those who lose income due to TB.

Unlike CHE, the catastrophic total costs approach which incorporates direct medical costs, direct non-medical costs, and overall indirect costs highlights the impact of income loss. It also provides a clearer description of the severity of the financial impact than the CHE approach does. This is indicated by the consistently higher mean gap in the TB and MDR-TB groups.

The determinants of catastrophic total costs shown in this study highlight both the magnitude of the problem of income loss and the need to address it properly. As well as aggravating barriers to TB treatment adherence, thereby potentially worsening TB outcomes, income loss increases the risk of catastrophic costs and even greater impoverishment. If a TB patient is the family breadwinner, the incidence of catastrophic total costs is doubled.

In MDR-TB patients, coming from a poor household was not a determinant of catastrophic total costs. We had assumed that most MDR-TB cases would come from poor households, but this proportion was in fact very low. Overall, the incidence of catastrophic total costs was also very high: irrespective of their income level, over half of MDR-TB-affected households experienced such costs.

As our findings provide insights that contrast with the perspective of CHE, they provide a new basis for estimating costs, and may thus have policy implications. As well as supporting the WHO's recommendation that the catastrophic total costs approach should be used, the main implication of our study is a strong recommendation to government that it should introduce a cost-mitigation policy and additional social protection beyond free medical services.[5,22] Forms of financial protection other than food/nutritional supplementation and travel vouchers may be required. Cash transfers could be made conditional on behavioral requirements such as continuing treatment. Microfinance programs are also a potential form of financial support,[33,34] but this strategy requires complex and expensive inputs. The government should target beneficiaries carefully, ensure the delivery to patients, provide incentives that induce patients to adhere to treatment, and should therefore consider reserving a budget that is large enough. As well as emphasizing financial incentives, it is imperative to tackle any stigma and discrimination in workplaces that can lead to income loss. The government should also strengthen the policy by supporting job protection or paid sick leave for formally employed TB patients.

The high incidence of catastrophic total costs among poor patients requires inputs within the UHC framework. The government should incorporate strategies for widening population coverage, for improving the availability, accessibility, and quality of public health facilities; and also for involving as many private health facilities as possible in the BPJS network. To conform with the ISTC, they should also ensure proper training.

This study has several limitations. First, in line with the WHO protocol, we collected data from TB patients who visited PHCs and excluded those who were treated in facilities that were not linked to the NTP. Neither did we include TB nor suspected TB patients who were unable to afford TB-related services or who dropped out of the diagnostic procedure or out of treatment. This may have led to an underestimation of the incidence of catastrophic total costs. Second, MDR-TB patients were only recruited in a pulmonary hospital in an urban area with a low proportion of poor households. We did not describe a situation in which patients were removed from the hospital to PHCs for taking MDR-TB drugs after sputum conversion, and dropped out from treatment. Third, although we interviewed patients with a structured questionnaire to help recall their spending, our findings may have been affected by recall biases. Finally, while our study results apply to the western part of Indonesia such as Java, Bali, and Sumatra, which constitute 80% of the Indonesian population,[35] some parts of Indonesia may have

different characteristics that require careful generalization, especially the islands and more remote areas.

Conclusions

Both TB and MDR-TB patients are in danger of falling into even deeper poverty. Travel costs, food/nutritional supplementation costs, and income loss all contribute to the incidence of catastrophic total costs. This risk is higher in patients from poor households, especially when they are breadwinners who lose their jobs. These findings suggest that measures beyond free medical services are required to mitigate the financial burden of households affected by TB, particularly for patients living in at-risk groups.

Ethics approval and consent to participate

We confirmed that all respondents received written and oral explanations of the study, and signed an informed consent form before the interview. Ethical clearance for this study was provided by the Ethical Committee at the Faculty of Medicine of Universitas Indonesia–Cipto Mangunkusumo Hospital, Jakarta Indonesia (No. 416/UN2.F1/ETIK/VI/2016); and the Ethical Committee at Persahabatan Hospital, Jakarta, Indonesia (No. DL.01.03/II.3/3817/2016).

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Chapter 4

Cost of seeking care for tuberculosis since the implementation of universal health coverage in Indonesia

Ahmad Fuady[1,2*] Tanja A.J. Houweling,[1] Muchtaruddin Mansyur,[2] Erlina Burhan,[3] Jan Hendrik Richardus[1]

[1]Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands; [2]Department of Community Medicine, Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia; [3]Department of Respiratory and Pulmonology, Persahabatan Hospital – Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia.

In Review

Abstract

Background:

Although tuberculosis (TB) patients often incur high costs to access TB-related services, it was unclear beforehand whether the implementation of universal health coverage (UHC) in Indonesia in 2014 would reduce direct costs and change the pattern of care-seeking behaviour. After its introduction, we therefore assessed TB patients' care-seeking behaviour and the costs they incurred for diagnosis, and the determinants of both.

Methods:

To assess their care-seeking behaviour, we interviewed adult TB patients in three areas of Indonesia – one urban, one suburban and one rural – in July-September 2016. All had been treated for at least one month. After establishing which direct and indirect costs they had incurred during the pre-diagnostic phase, we calculated the total costs (US Dollars). To identify the determinants of these costs, we applied a general linear mixed model to adjust for our cluster-sampling design.

Results:

Ninety-three patients of the 282 included in our analysis (33%) first sought care at a private clinic. The preference for such clinics was higher among those living in the rural district (aOR 1.88, 95% CI 0.85-4.15, P=0.119) and among those with a low educational level (aOR 1.69, 95% CI 0.92-3.10, P=0.090). Visiting a private clinic as the first contact also led to more visits (β 0.90, 95% CI 0.57-1.24, P<0.001) and higher costs than first visiting a Primary Health Centre, both in terms of direct costs (β=16.87, 95%CI 10.54-23.20, P<0.001) and total costs (β=18.41, 95%CI 10.35-26.47, P<0.001).

Conclusion:

Despite UHC, high costs of TB seeking care remain, with direct medical costs contributing most to the total costs. First seeking care from private providers tends to lead to more pre-diagnostic visits and higher costs. To reduce diagnostic delays and minimize patients' costs, it is essential to strengthen the public-private mix and reduce the fragmented system between the national health insurance scheme and the National TB Programme.

Background

Studies in Asian countries suggest that the private healthcare sector has the potential to play an important role in national and global tuberculosis (TB) control.[1-4] Many studies have shown that patients initially visit private providers to relieve them from TB-related symptoms.[5] In Indonesia, many patients also prefer first to seek care from private providers [4]. However, private providers often fail to comply with TB practice guidelines, including those for the screening and diagnosis of TB cases.[4,6] In the pre-diagnostic phase, failure to comply with TB practice guidelines may lead to missed TB cases. Patients who continue to have TB related symptoms then have many healthcare visits,[7] leading to diagnostic delays and high costs during seeking care.[8,9] This eventually worsens disease prognosis at the individual level, increases costs in the household level, and spreads TB in the community.[8,10]

In 2014, Indonesia started implementing a universal health coverage (UHC) scheme, also called the Indonesian National Health Insurance scheme (*Jaminan Kesehatan Nasional*, JKN), to ensure people's access to healthcare. This insurance scheme is managed by the Social Security Agency for Health *(Badan Penyelenggara Jaminan Sosial Kesehatan*, BPJS-K) and covers all essential care services, including TB diagnostic tests through healthcare providers that are linked to the BPJS-K.[9,11] In the first four years after the JKN was implemented, the number of private providers linked to the BPJS-K – clinics and solo practices alike – increased substantially, from 6,369 private providers to 11,507.[12]

However, BPJS-K is not directly linked to the network of the Indonesian National Tuberculosis Program (NTP), which are national level government boards that are responsible for TB control. Private providers that are linked to the BPJS-K are therefore also not necessarily linked to the NTP. Responding to this problem, the NTP launched a guideline of TB care to coordinate the care with the BPJS-K.[13] Although there has been no direct linkage between the NTP and BPJS-K, the private providers that are linked with BPJS-K can conduct the TB tests in their laboratories, if available, or can refer suspected TB patients for diagnostic tests to a BPJS-K-linked facility.[13] All consultation and diagnostic test fees are covered by the BPJS-K. If the suspected patient has received the final TB diagnosis, the private providers can refer the patient to the NTP-linked facilities to receive free TB treatment. As most TB patients seek initial care

with a private provider,[6] this coordinated scheme between BPJS-K and the NTP is assumed to reduce patient's direct costs during the pre-diagnostic phase.

Nevertheless, there is no evidence available on the costs incurred during the pre-diagnostic phase of TB and TB patients' care seeking behaviour since the implementation of UHC in Indonesia. It is therefore unclear to which extent UHC has saved patients from high costs during this phase. The aims of this study are to assess the costs incurred before diagnosis by patients seeking care for TB after the implementation of UHC in Indonesia, and to assess care-seeking behaviour of TB patients in this period on the basis of the first contact facility and the number of healthcare visits.

Methods

Study design and setting

To assess patients' TB care-seeking behaviour and the costs they incurred during the pre-diagnostic phase, we conducted a cross-sectional study that was a part of a larger study on measuring catastrophic costs in Indonesia [9]. In this study, we interviewed patients who had undergone TB treatment in PHCs (i.e. public facilities for primary-level care). We selected three districts in Java, the most populous island of Indonesia, purposively to represent urban (Jakarta), suburban (Depok), and rural (Tasikmalaya) areas of Indonesia.

Study population

We included all subjects who met the inclusion criteria of our main study, which were adult patients who had received TB treatment in a PHC for at least one month. We excluded extra-pulmonary cases, as these are diagnosed using different methods that may result in bias on pre-diagnostic costs.

Sampling method

The sample size and sampling methods in this study followed that of our larger study, which assumed an incidence of catastrophic costs due to TB of 20-30%.[9] With

assumptions of a power of 0.80, an error of 0.05, and a ratio of TB patients of 1:1:1 in each district, we required 90 patients per district. In each district, we included all the PHCs that were linked to the Indonesian NTP in our sampling framework, and then randomly selected five PHCs per district. We chose only PHCs since most of TB patients were treated in PHCs. In each PHC, we selected consecutive adult TB patients until we reached at least 90 patients per district. If the sample size was not reached, we randomly selected additional PHCs until we obtained at least 90 patients per district. In total, 19 PHCs were included in our study.

Data collection

All patients were interviewed by four medical students and six public health graduates we had recruited and trained for the purpose. As a part of our main study on measuring catastrophic costs, the interview was conducted during the TB treatment phase – 48% of patient in their intensive phase and 52% of patients in their continuous phase.[9] To interview the patients and/or the drug observer who accompanied each patient as a direct observation of treatment (DOT) supporter, these interviewers used the adapted and validated Bahasa Indonesia version of the Tool to Estimate Patient Costs.[14]

Retrospectively, each respondent listed each healthcare facility he or she had visited between developing TB-related symptoms (e.g., chronic cough, bloody cough, weight loss, or night sweating) and the establishment of their TB diagnosis.[14] We also calculated the number of healthcare visits and costs incurred during the pre-diagnostic phase, and then assessed the determinants of the number of visits and costs.

Care seeking behaviour

First, to assess patients' care-seeking behaviour, we established the nature of their first contact facility, i.e., a primary health centre (PHC); a private clinic (whether a solo practice or part of a multiple practice); a public hospital; a private hospital; or 'other', such as a pharmacy, a practitioner of alternative medicine, or a *mantri* (i.e., a registered nurse practicing as an unauthorized physician). We then assessed whether the first contact facility was associated with the district (urban/suburban/rural), household income level (poor/non-poor household), educational level (low/middle-high), health

insurance status (being covered/not being covered by the BPJS-K scheme), and formal employment (yes/no).

Number of visits

Second, we calculated the number of healthcare visits made during the pre-diagnostic phase. To assess the determinants of the number of visits, we also included first contact as an independent variable, together with the other independent variables.

Costs of care seeking

Third, we asked patients the details of all the types of cost they had incurred in each facility visited during the pre-diagnostic phase, i.e., direct medical costs, direct non-medical costs, and indirect costs related to seeking care for their TB-related symptoms. The definitions of cost items used in this study conformed with the WHO handbook on TB costs survey.[15] The direct medical costs included all out-of-pocket (OOP) payments to the healthcare facilities for medical fees, such as administrative charges and the cost of drugs, laboratory analyses, or X-ray examinations. The direct non-medical costs included the cost of food and travel for patients and/or their guardian during their visits to healthcare facilities. The indirect costs consisted of loss of income incurred by the patients and their guardians on their visits to healthcare facilities. The total costs were the sum of direct medical costs, direct non-medical costs, and indirect costs. All costs were provided in Indonesian Rupiahs (IDR) and then converted to US dollars using the World Bank's average exchange rate for 2015 (1 USD = 13 389.41 IDR). We then assessed whether the total costs, direct costs, and indirect costs were associated with the first contact, district, household income level, educational level, health insurance status, and formal employment.

Data management and analysis

Data were double-entered into Microsoft Excel 2010 and EpiInfo version 7 (CDC, Atlanta) and then exported to IBM SPSS 21 for data analysis. Number of visits and costs data were displayed as means and their 95% confidence intervals (CIs) while

categorical variables as numbers and proportions (%). To examine the determinants of the patients' first contact facility, the number of visits, and their costs during the pre-diagnostic phase, we applied the generalized linear mixed models (GLMMs) with random effects to adjust for our cluster sampling design (19 PHCs), since we selected the PHCs randomly. We assessed the goodness of fit for models by examining the Akaike corrected and the Bayesian information criterion provided by SPSS. To analyse the determinants of the first health-service contact, we estimated crude odds ratios (cORs), adjusted odds ratios (aORs), and their 95% CIs with a target distribution of multinomial regression. To analyse the determinants of number of visits and costs incurred by patients and their family, we established crude and adjusted GLMM regression coefficients (β) and their 95% CIs with a target distribution of linear regression.

Ethical issues

Before the interview, we provided all respondents with a written and oral explanation of the study. Only those who had signed an informed consent form were interviewed. Before the study, we received ethical clearance from the Ethical Committee at the Faculty of Medicine of Universitas Indonesia–Cipto Mangunkusumo Hospital, Jakarta, Indonesia (No. 416/UN2.F1/ETIK/VI/2016).

Table 1 First point of care and place of TB diagnosis of a sample of 282 TB patients.

Healthcare service	First point of care		Place of diagnosis	
	n	%	N	%
Primary health centre	127	45	164	58
Private clinic	93	33	43	15
Public hospital	32	11	50	18
Private hospital	20	7	25	9
Other health provider*	10	4	0	0

*Pharmacy, practitioner of alternative medicine, *mantri*, or other health provider.

Results

We included the interviews of 282 patients. Whereas a PHC had been the first point of diagnostic care-seeking for 45% of them, 33% had first sought care at a private clinic, 11% at a public hospital, 7% at a private hospital, and 4% at a pharmacy, practitioner of alternative medicine, or other healthcare provider. (Table 1) A majority of patients (58%) had been diagnosed at a PHC. The remainder had been diagnosed at a private clinic (15%), public hospital (18%), or private hospital (9%) before they were referred to PHCs for TB treatment.

Figure 1 shows the most common care-seeking patterns identified in this study. Seventeen percent of patients had been diagnosed during their first visit at PHC. This was higher than the percentage of patients who had been diagnosed during their first visit to any of the other healthcare settings. All patients who had first sought care at a pharmacy, practitioner of alternative medicine or other healthcare provider had moved to another provider – usually a private clinic – for their second visit.

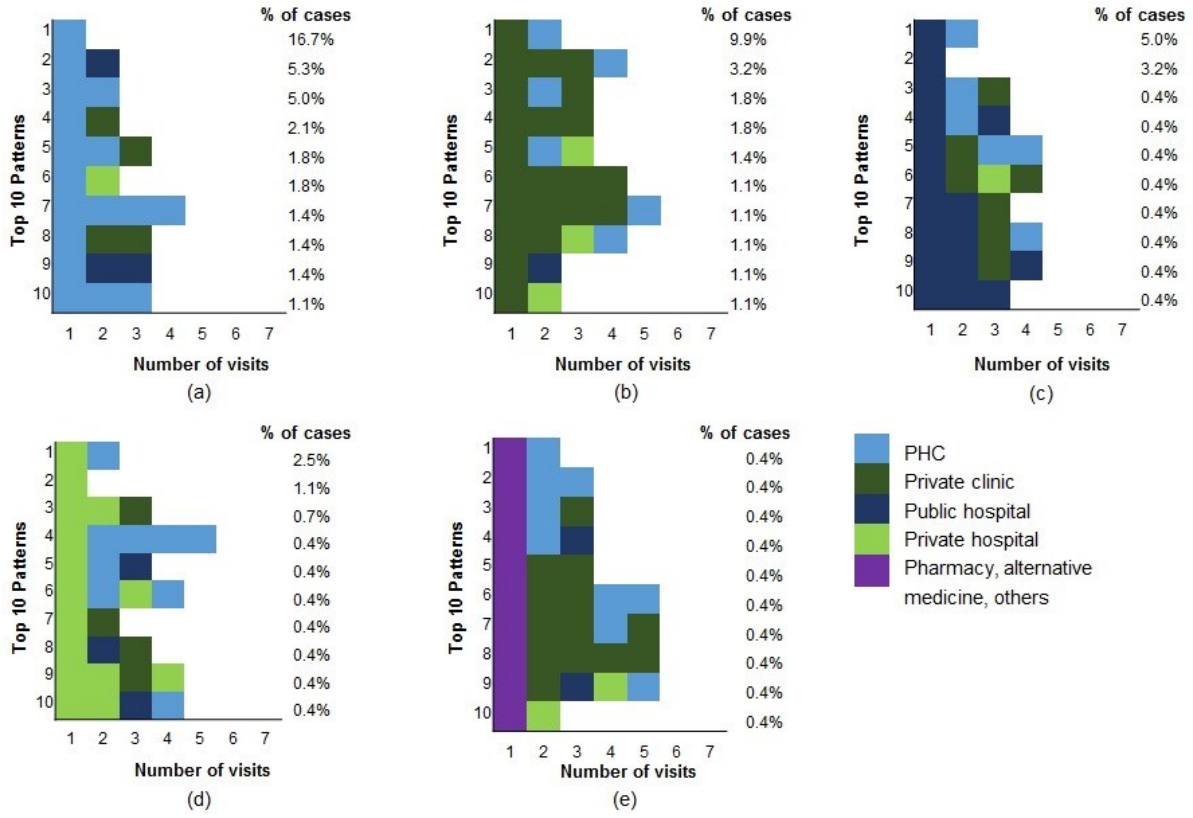

Figure 1 The care-seeking pattern of TB patients onwards of their first contact.

The figure shows the top 10 care-seeking patterns that followed the first contact with each of the following: (a) a PHC, (b) a private clinic, (c) a public hospital, (d) a private hospital, and (e) a pharmacy, practitioner of alternative medicine, or other health provider. Each coloured block indicates the type of

healthcare provider visited. Each rightmost box indicates the provider where the TB diagnosis was confirmed. The percentages to the right of each graph are the percentages of each patterns. Eighteen percent of patterns are not captured in these graphs.

Table 2 shows that in the urban and suburban districts, more patients initially sought care at a PHC than at another healthcare facility. In contrast, among patients with low education level, the proportion of those who initially sought care at a private clinic was higher than at another healthcare facility.

Table 2 Distribution of patients by point of first contact.

Characteristics	**Primary health centre** *N (%)*	**Private clinic** *N (%)*	**Public hospital** *N (%)*	**Private hospital** *N (%)*	**Other health provider†** *N (%)*	**Total**
Number of patients	*127 (45)*	*93 (33)*	*32 (11)*	*20 (7)*	*10 (4)*	*282 (100)*
Districts						
Urban	51 (54)	26 (27)	11 (12)	4 (4)	3 (3)	95 (100)
Suburban	40 (44)	25 (28)	10 (11)	13 (14)	2 (2)	90 (100)
Rural	36 (37)	42 (43)	11 (11)	3 (3)	5 (5)	97 (100)
Household income level‡						
Non-Poor	51 (48)	30 (28)	12 (11)	13 (12)	1 (1)	107 (100)
Poor	76 (43)	63 (36)	20 (11)	7 (4)	9 (5)	175 (100)
Education level±						
Middle-High	89 (49)	50 (27)	22 (12)	15 (8)	7 (4)	183 (100)
Low	38 (38)	43 (43)	10 (10)	5 (5)	3 (3)	99 (100)
National health insurance						
Not covered	48 (44)	41 (37)	8 (7)	7 (6)	6 (5)	106 (100)
Covered	79 (46)	52 (30)	24 (14)	13 (8)	4 (2)	176 (100)
Workers in informal sectors						
No	41 (51)	25 (31)	7 (9)	5 (6)	3 (4)	81 (100)
Yes	86 (43)	68 (34)	25 (12)	15 (7)	7 (3)	201 (100)

† Pharmacy, alternative medicine, *mantri*, and other health providers; ‡ household earning below 1.9 USD per capita per day was classified as a poor household; ± a patient who did not graduate from elementary school was classified as having low education level.

Table 3 shows that more patients in the rural district preferred to seek care first at a private clinic (cOR 2.27, 95% CI 1.14-4.53, *P*=0.020). Seeking inital care at a private provider rather than a PHC was also greater among patients with a low educational level than among those with a middle to high educational level (cOR 1.93, 95% CI 1.09-3.41, *P*=0.024). Despite the borderline statistical significance of the result, multivariable analysis showed that the odds of seeking care at a private clinic rather than at a PHC was higher in the rural district (aOR 1.87, 95% CI 0.85-4.15, *P*=0.119) and in patients with low education level (aOR 1.69, 95% CI 0.51-1.65, *P*=0.090). There were no statistically significant differences regarding first contact preferences for the following: between patients with insurance and without insurance; between patients living in a poor household and a non-poor household; and between patients with and without formal work.

Table 3 Determinants of the first point of health-service contact (private clinic or primary health centre).

Characteristics	**Private clinic** N (%)	**PHC[a]** N (%)	***P***	**cOR (95% CI)**	***P***	**aOR (95% CI)**
Districts						
Urban[a]	26 (27)	51 (54)		1		1
Suburban	25 (28)	40 (44)	0.557	1.24 (0.60-2.55)	0.462	1.32 (0.63-2.76)
Rural	42 (43)	36 (37)	0.020	2.27 (1.14-4.53)	0.119	1.88 (0.85-4.15)
Household income level‡						
Poor	63 (36)	76 (43)	0.355	1.32 (0.74-2.35)	0.824	1.07 (0.57-2.01)
Non-Poor[a]	30 (28)	51 (48)		1		1
Education level±						
Low	43 (43)	38 (38)	0.024	1.93 (1.09-3.41)	0.090	1.69 (0.92-3.10)
Middle to high[a]	50 (27)	89 (49)		1		1
National health insurance						
Covered	52 (30)	79 (46)	0.468	0.81 (0.46-1.43)	0.768	0.92 (0.51-1.65)
Not covered[a]	41 (37)	48 (44)		1		1
Workers in informal sectors						
Yes	68 (34)	86 (43)	0.364	1.32 (0.72-2.41)	0.284	1.40 (1.76-2.58)
No[a]	25 (31)	41 (51)		1		1

[a]Reference category; ‡ household earning below 1.9 USD per capita per day was classified as a poor household; ± a patient who did not graduate from elementary school was classified as having low education level.

The average number of visits during the pre-diagnostic phase was 2.56 (95% CI 2.41-2.71). Patients who first sought care at private clinics and other health care providers had more visits until their diagnosis was confirmed than patients who first visited a PHC (aβ 0.90, 95% CI 0.57-1.24, *P* <0.001 for private clinics and aβ 1.77, 95% CI 0.97-2.57, *P* <0.001 for other health care providers). (Table 4). There were no statistically significant differences in the number of visits regarding the following determinants: district, household income level, educational level, having insurance, and employment status.

Table 4 Determinants of the number of healthcare visits during the pre-diagnostic phase.

Variables	**No of visits** mean (95% CI)	**cβ (95% CI)**	***P***	**aβ (95% CI)**	***P***
Total number of visits	*2.56 (2.41-2.71)*				
First contact facility					
Primary Health Centre	2.18 (1.96-2.41)	Ref		Ref	
Private clinic	3.06 (2.83-3.30)	0.89 (0.57-1.22)	<0.001	0.90 (0.57-1.24)	<0.001
Public hospital	2.13 (1.77-2.48)	-0.07 (-0.55-0.41)	0.766	-0.08 (-0.56-0.41)	0.750
Private hospital	2.65 (2.06-3.24)	0.44 (-0.14-1.02)	0.140	0.39 (-0.20-0.99)	0.194
Other health provider	3.9 (2.66-5.14)	1.70 (0.91-2.49)	<0.001	1.77 (0.97-2.57)	<0.001
District					
Urban	2.49 (2.18-2.63)	Ref		Ref	
Suburban	2.63 (2.37-2.90)	0.21 (-0.29-0.70)	0.406	0.17 (-0.31-0.66)	0.484
Rural	2.56 (2.34-2.78)	0.11 (-0.39-0.62)	0.667	-0.05 (-0.57-0.48)	0.861
Household income level‡					
Poor	2.58 (2.38-2.77)	0.07 (-0.25-0.40)	0.656	0.02 (-0.34-0.31)	0.927
Non-poor	2.53 (2.29-2.78)	Ref		Ref	
Education level±					
Low	2.66 (2.39-2.92)	0.16 (-0.17-0.49)	0.336	0.14 (-0.22-0.43)	0.526
Middle-high	2.51 (2.32-2.70)	Ref		Ref	
National health coverage					
Covered	2.58 (2.37-2.79)	0.07 (-0.25-0.39)	0.673	0.18 (-0.13-0.49)	0.259
Not covered	2.53 (2.32-2.74)	Ref		Ref	
Workers in informal sectors					
Yes	2.55 (2.37-2.72)	-0.07 (-0.41-0.27)	0.692	-0.12 (-0.44-0.21)	0.480
No	2.59 (2.29-2.90)	Ref		Ref	

β is the GLMM coefficient of the expected change in the number of visits compared to the reference category; cβ, crude coefficient β; aβ, adjusted coefficient β; CI, confidence interval; Ref, reference; P, value of significance; ‡ household earning below 1.9 USD per capita per day was classified as a poor household; ± a patient who did not graduate from elementary school was classified as having low education level.

The average total cost incurred during the pre-diagnostic phase was USD 22 (95% CI 18-26). It consisted mainly of direct costs (USD 16, 95% CI 13-19). (Table 5) Visiting a private clinic as the first point of contact led to statistically significantly higher costs than visiting a PHC as the first contact, both in terms of direct costs (β 16.87, CI 95% 0.54-23.20, $P<0.001$) and of total costs (β 18.41, CI 95% 10.35-26.47, $P<0.001$). Patients who visited a private hospital as the first contact also incurred statistically significantly higher direct costs (β 28.38, CI 95% 17.18-39.58, $P<0.001$) and total costs (β 24.96, CI 95% 10.64-39.28, $P=0.001$) than those visiting a PHC as the first contact. The direct medical costs incurred by patients who first sought care at private clinics (USD 21; 95% CI USD 15-28) and private hospitals (USD 32; 95% CI USD 17-48) were significantly higher than those who first sought care at PHCs (USD 5; 95% CI USD 3-7), while travel costs between private providers and PHCs did not differ significantly (See Annex E).

Despite involving a higher number of visits, first visiting a pharmacy, practitioner of alternative medicine or other health provider did not lead to significantly higher costs than those incurred by patients who first sought care at a PHC. Between districts, insurance coverage, household income level, and education level, the differences in the total costs, direct costs, and indirect costs incurred were not statistically significant. Indirect costs during the pre-diagnostic phase were associated with employment status. In addition, patients who were formally employed had higher indirect costs than patients who did not have a job or were not formally employed (β 3.92, CI 95% 0.88-6.96, $P=0.012$). No other variables determined the indirect costs.

Table 5 Determinants for cost of seeking care, in USD.

Variables	Total costs			Direct costs			Indirect costs		
	Mean (95% CI)	β (95% CI)	*P*	Mean (95% CI)	β (95% CI)	*P*	Mean (95% CI)	β (95% CI)	*P*
Costs	*22 (18-26)*			*16 (13-19)*			*6 (4-7)*		
First contact facility									
Primary Health Centre	14 (10-17)	Ref		8 (6-10)	Ref		6 (4-8)	Ref	
Private clinic	32 (23-41)	18.41 (10.35-26.47)	<0.001	25 (18-32)	16.87 (10.54-23.20)	<0.001	7 (4-10)	1.75 (-1.44-4.95)	0.280
Public hospital	18 (9-27)	5.30 (-6.46-17.06)	0.376	13 (7-18)	4.98 (-4.22-14.18)	0.288	6 (1-10)	0.19 (-4.48-4.85)	0.937
Private hospital	37 (22-52)	24.96 (10.64-39.28)	0.001	36 (20-51)	28.38 (17.18-39.58)	<0.001	1 (0-3)	-3.50 (-9.19-2.18)	0.226
Other health provider	18 (7-29)	5.38 (-14.02-24.78)	0.586	14 (5-24)	6.83 (-8.40-22.06)	0.378	4 (-1-8)	-1.32 (-8.99-6.36)	0.736
District									
Urban	23 (14-31)	Ref		16 (9-22)	Ref		7 (4-10)	Ref	
Suburban	20 (15-25)	-1.18 (-12.55-10.20)	0.839	16 (11-21)	1.81 (-6.89-10.50)	0.683	3 (2-5)	-3.23 (-7.94-1.48)	0.178
Rural	23 (19-28)	1.80 (-9.79-13.39)	0.76	17 (13-20)	1.57 (-7.22-10.36)	0.725	7 (5-9)	0.23 (-4.62-5.08)	0.926
Household income level‡									
Poor	22 (17-28)	1.93 (-5.77-9.63)	0.622	17 (13-21)	1.59 (-4.57-7.74)	0.612	6 (4-7)	0.16 (-2.80-3.11)	0.918
Non-poor	21 (16-26)	Ref		15 (11-19)	Ref		6 (3-8)	Ref	
Education level±									
Low	22 (18-27)	0.42 (-7.40-8.24)	0.916	17 (13-20)	0.61 (-5.638-6.86)	0.848	6 (4-8)	-0.22 (-3.25-2.75)	0.869
Middle-high	22 (16-27)	Ref		16 (12-20)	Ref		6 (4-8)	Ref	
National health insurance									
Covered	20 (16-23)	-5.50 (-13.17-2.17)	0.159	14 (12-17)	-4.785 (-10.89-1.32)	0.124	5 (4-7)	-0.64 (-3.59-2.32)	0.672
Not covered	26 (18-34)	Ref		19 (13-26)	Ref		7 (4-9)	Ref	
Workers in informal secto									
Yes	23 (18-28)	3.26 (-4.82-11.34)	0.428	16 (12-20)	-0.52 (-7.04-6.00)	0.876	7 (5-9)	3.92 (0.88-6.96)	0.012
No	19 (15-24)	Ref		16 (12-20)	Ref		3 (2-4)	Ref	

Direct costs include those incurred by patients and/or their guardians during the pre-diagnostic phase for consultation, administrative fees, diagnostic tests (sputum and/or X-ray examination), food, and travel. Indirect costs include their income losses due to visits to healthcare facilities during the pre-diagnostic phase. Total costs are the sum of direct and indirect costs. β is the GLMM coefficient of the expected change in the number of visits compared to the reference category; cβ, crude coefficient β; aβ, adjusted coefficient β; CI, confidence interval; Ref, reference; P, value of significance; ‡ Household earning below 1.9 USD per capita per day was classified as a poor household. ± A patient who did not graduate from elementary school was classified as having low education level.

Discussion

Our results show that patients still incur high costs while seeking TB care. Direct medical costs contributed most to the total costs of TB care seeking, despite the implementation of UHC in Indonesia. Most patients who were treated for TB in a PHC had started their care-seeking in private sector. The number of those who first sought care at a private clinic first was significantly greater among patients who lived in the rural district and among those with a lower educational level. Before being diagnosed with TB, patients who had first sought care at such clinics made more healthcare visits and had higher costs than those whose first point of contact was a PHC.

Rural patients' preference for starting to seek care at a private clinic may have been affected by the greater distance they had to travel to a PHC. The number of PHCs in these areas is limited, the cost of transport to them is higher, and the waiting times can be long.[16] This encourages patients to visit any private healthcare provider – whether clinic, solo practice or other – that is closer to their house.

However, to have their diagnosis of TB confirmed, patients whose first point of contact was a private clinic needed more visits than those who first visited a PHC. This higher number of visits may have been due to the poorer TB-service readiness of private clinics, most of which – particularly private solo practices – do not have appropriate facilities for TB diagnostic tests, i.e., a laboratory for sputum smear examination.[17] To solve this problem, we suggest that most clinics use sputum smear fixation and deliver the preparation for diagnosis to a referral PHC or a clinic linked with the BPJS-K.[13]

Our findings also suggest that seeking care first at a private clinic or private hospital led to significantly higher costs during the pre-diagnostic phase. Except when covered by health insurance, each visit to a private hospital is costly.[18,19] This explains why, despite the limited number of visits, high costs were incurred at private hospitals. However, while the high cost of private clinics sometimes resulted from the high costs per visit, it also may be resulted from a high number of visits or from a combination of both.

Patients who first sought care at a pharmacy, practitioner of alternative medicine or other healthcare provider had a higher number of visits than those who started care-seeking at PHCs. However, this high number of visits did not lead to significantly higher costs for diagnosis. This may have been because the costs of simple, generic medicine in a pharmacy or of consultations for alternative medicine were low.

Despite the implementation of UHC in Indonesia, excessive visits and costs during the pre-diagnostic phase remain. Although this study did not compare the situation before and after the implementation of UHC, we showed that there were no significant differences in number of visits and costs between patients who were and were not covered by national health insurance.

Excessive visits and costs can result in diagnostic delays, potential catastrophic costs during treatment, and poor outcome.[10,20] To prevent high number of visits and high costs, the integration between the national health insurance and the NTP, which is still fragmented, should be improved.[21] Currently, there has been no direct link between the national health insurance system and the NTP. Private providers – despite linked to the BPJS-K – often unaware of the national tuberculosis guidelines and of TB referral system under the NTP.[4] The current practice of TB current guidelines in private providers seems not optimal. There has been also lack of incentives from the national health insurance to improve the quality of TB care in private sector.[22] Therefore, comprehensive strategies are imperative.

To solve the fragmented system in TB care, the national health insurance needs to develop a mechanism of incentives whereby private physicians and clinics can screen and diagnose TB cases accurately and refer the case to facility where TB diagnostic tests and treatment are fully covered. In its pay-for-performance criteria,[22] for example, BPJS-K should include the quality of the TB services a clinic provides. A contract of service provision that is signed between the BPJS-K and private providers should consider the readiness of the TB services including the availability of diagnostic tests, the adherence with TB management guidelines, and prior attendance of TB training. In addition, the strategies should include efforts to increase patients' awareness, to reduce stigma and discrimination, to improve TB diagnostic options, and to increase the number of PHCs in rural districts.

This study has two main limitations. The first is our collection of data from patients who had ended up at a PHC for TB treatment, and thus our exclusion of those who had had TB treatment from a private provider. This may have led us to overestimate PHCs as the first point of contact and to underestimate the number of pre-diagnostic visits and the costs incurred during the pre-diagnostic phase. It may also have led to a misleadingly high figure for the number of visits – by at least one visit – by patients whose first point of care had not been a PHC, particularly if this visit had involved a healthcare provider

that could not itself diagnose TB. The second limitation is that, since we relied on patients' memory to obtain the information, the number of visits and the costs incurred may also have been affected by recall bias. A patient may not remember the frequency and cost of buying medicine in a drug store or pharmacy, and thereby underestimate the number of visits and the total pre-diagnostic costs.

The provision of TB services in Indonesia is similar to health-service delivery in other high TB-burden countries in Asia that need to improve their public-private mix. However, our findings require careful generalization before being applied to other countries or even to other regions of Indonesia. As this study was conducted only on the island of Java, it does not necessarily reflect the situation throughout Indonesia.

Conclusion

Despite the UHC, high costs of TB seeking care remain, with direct medical costs contributing most to the total costs. The preference of people with TB first to seek diagnosis from a private provider rather than a PHC leads to more pre-diagnostic visits and higher costs. The UHC scheme alone is not enough to improve TB control and reduce patients' costs. A comprehensive strategy is required to improve TB-related services in the private healthcare sectors. To reduce diagnostic delays and minimize patients' costs, it is essential to reduce the fragmented system between the national health insurance scheme and the National TB Programme, to improve the quality of TB care in the private sector, and to improve the availability of PHCs, particularly in rural areas.

Ethics approval and consent to participation

We received ethical clearance for this study from the Ethical Committee at the Faculty of Medicine of Universitas Indonesia – Cipto Mangunkusumo Hospital, Jakarta Indonesia (No. 416/UN2.F1/ETIK/VI/2016). Before interviewing selected TB patients, we provided them with written and oral explanations, and also with the informed-consent form necessary for their approval as subjects of this study.

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Chapter 5

Catastrophic costs due to tuberculosis worsen treatment outcomes: a prospective cohort study in Indonesia

Ahmad Fuady, MD, M.Sc[1,2*] Tanja A.J. Houweling, Ph.D,[1] Muchtaruddin Mansyur, MD, PhD,[2] Erlina Burhan, MD, Ph.D,[3] Jan Hendrik Richardus, MD, Ph.D[1]

[1]Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands; [2]Department of Community Medicine, Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia; [3]Department of Respiratory and Pulmonology, Persahabatan Hospital – Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia.

In Review

Abstract

Background:

While the incidence of catastrophic costs due to tuberculosis (TB) remains high, there is little evidence about their impact on TB treatment outcomes and adherence. We assessed their effect on treatment outcomes and adherence in Indonesia.

Methods:

We interviewed 282 adult TB patients who underwent TB treatment in urban, suburban, and rural districts of Indonesia. One year after the interview, we followed up treatment adherence and outcomes. We applied multivariable analysis using generalized linear mixed models.

Results:

Follow-up was complete for 252/282 patients. Eighteen (7%) patients had unsuccessful treatment and 40 (16%) had poor adherence. At a threshold of 30% of annual household income, catastrophic costs negatively impacted treatment outcomes (aOR=4.15, 95%CI=1.15-15.01). At other thresholds, the associations showed a similar pattern, but were not statistically significant. The association between catastrophic costs and treatment adherence is complex because of reverse causation. After adjustment, catastrophic costs negatively affected treatment adherence at the 10% and 15% threshold (aOR=2.11, 95%CI=0.97-4.59, *P*=0.059 and aOR=2.06, 95%CI=0.95-4.46, *P*=0.07). At other thresholds, there was no evidence of such an effect.

Conclusions:

Catastrophic costs negatively affect TB treatment outcomes and treatment adherence. To eliminate TB, it is essential to mitigate catastrophic costs.

Keywords: Catastrophic costs, Indonesia, Treatment adherence, Treatment outcomes, Tuberculosis.

Introduction

Tuberculosis (TB) often result in severe economic consequences for TB-affected households.[1] The latest World Health Organization (WHO) End TB Strategy aims by 2020 to reduce to zero percent the percentage of TB-affected families that face catastrophic costs.[2] However, attaining this target is challenging. In a simulation of eight scenarios, Fuady *et al*. showed that, although the provision of a cash transfer to TB-affected households would reduce the incidence of catastrophic costs due to TB, the incidence would not reach the zero-percent target.[3] This failure is due to the high variability of costs between TB patients, particularly those due to income loss. If the value of cash transfer provided were the same for all patients, it would not be possible to eliminate catastrophic costs. This finding raises the question of whether eliminating catastrophic costs –apart from its importance as a proxy of poverty– is a rational target to be achieved.

There are various definitions of catastrophic costs. Given that eliminating the incidence of catastrophic costs is a target of the WHO End TB Strategy, the definition of TB-related catastrophic costs issued by the WHO is the most appropriate to use. The latest TB costs survey handbook of the WHO defines catastrophic costs as the total costs—i.e., all direct and indirect costs, including income loss, that exceed a specific threshold of a household's annual income.[4] In Peru, Wingfield *et al.* showed that TB-related catastrophic costs were associated with adverse TB outcomes and suggested a threshold of 20% of annual household income to define catastrophic costs.[5] However, there is a paucity of evidence from other countries, especially from TB high-burden countries.

Indonesia is such a TB high-burden country. Despite the availability of free treatment, Indonesia has a high incidence of TB-related catastrophic costs: 36% in TB-affected households and 83% in MDR-TB-affected households.[6] Income loss is the main driver of these costs. Catastrophic costs during the course of treatment may affect treatment adherence and treatment outcomes. Patients may quit treatment altogether or they may interrupt it and thereby extend it, and –as a consequence– they may fail to be cured, or may even die during treatment. There is nonetheless no evidence on the impact of catastrophic costs on TB treatment outcomes and treatment adherence from this high-burden country. We aimed to establish the extent to which catastrophic costs in TB-affected Indonesian households affect TB treatment outcomes and adherence.

Material and methods

Study design

To assess the effect of catastrophic costs on patients' TB treatment adherence and outcomes, we conducted a cohort study in three districts in Indonesia, each with a different level of urbanization: Jakarta (urban), Depok (suburban), and Tasikmalaya (rural). In each district, we identified all primary health centers (PHCs) that delivered TB treatment services and were also linked to the Indonesian national tuberculosis program (NTP). For inclusion in our study, we randomly selected 5-8 PHCs per district. In total, 19 PHCs were included. In the baseline study (July-September 2016), we interviewed 282 TB patients aged 18 years old or above who had undergone TB treatment for at least one month, or had completed treatment no more than one month previously.[6] One year after the interview, we followed up their TB treatment adherence and TB treatment outcomes. We excluded TB patients whose treatment had not been evaluated, and patients who had been transferred to other health facilities.

Treatment outcome and adherence

As the WHO had set treatment outcome as an essential indicator in TB control programs,[7] treatment outcome was the primary outcome measured in this study. To evaluate patients' treatment outcomes, we examined their medical records (TB 01 forms) and cross-checked the data with the PHCs' TB record (TB 03 form). We used the definitions and classification of treatment outcome issued by the WHO, defining treatment outcome as successful if a patient had been cured or had completed TB treatment, and as unsuccessful if a patient had been lost to follow-up, had died, or if the treatment had failed.[8] (Table 1)

Table 1 Primary and secondary outcomes in this study

Outcomes	Definition
Primary outcome: treatment outcomes	
Successful treatment	*The sum of cured and completed TB cases.*
a. Cured	A TB patient who had a positive sputum smear or culture at the beginning of TB treatment but had a negative sputum smear or culture in the last month of treatment and on at least one previous occasion.
b. Completed	A TB patient who completed treatment but who, in the last month of treatment and on at least one previous occasion, did not have any proof of a negative sputum smear or culture result.
Unsuccessful treatment	*Died, failed, or lost to follow-up.*
a. Died	A TB patient who died for any reason during the course of treatment.
b. Failed	A TB patient who still had a positive sputum smear or culture after 5 months or more of TB treatment.
c. Lost to follow-up	A TB patient whose treatment had been interrupted for two consecutive months or more.
Secondary outcome: treatment adherence	
a. Good treatment adherence	A patient who treatment had been successful and whose treatment period had not exceeded the expected end-of-treatment date by 14 days or more.
b. Poor treatment adherence	Sum of patients whose treatment period had exceeded the expected end-of-treatment date by 14 days or more than, plus cases lost to follow-up.

Since catastrophic costs are also assumed to reduce treatment adherence, we evaluated treatment adherence as a secondary outcome. However, there is no commonly agreed definition of TB non-adherence. By defining non-adherent patients as those who had missed at least one prescribed dose of TB drug, some studies use stringent criteria,[9, 10] while other criteria are less stringent, such as having interrupted treatment for more than one month, or never having been under supervision.[11-15] We defined poor adherence as applying (a) to a patient who had been lost to follow-up— indicating that he or she had not adhered to treatment— or (b) to a patient whose treatment had been successful, but the treatment period had exceeded the expected end-of-treatment date by 14 days or

more. To assess the effect of catastrophic costs on treatment adherence, we excluded patients who had died and those whose treatment had failed.

Catastrophic costs

In the baseline study, we interviewed patients about the total TB-related costs their household had incurred since the pre-diagnostic phase until the patients stopped treatment. We used the *Tool to Estimate Patient Costs* that has been adapted to the Indonesian context.[4, 16] In compliance with the definition in the WHO handbook, total costs consisted of direct medical costs (i.e., administration costs, laboratory tests and X-ray examination costs, drug costs, hospitalization costs, and adverse drug-effects costs); direct non-medical costs (i.e., transportation costs, food costs, and the costs of food supplements); and income loss.[4]

To calculate administration costs and food costs, we multiplied the number of visits by the administration fees and food costs incurred during visits. To measure the total transportation costs, we multiplied single travel costs for a return visit by the number of visits during treatment. The number of visits was recorded in the patient's medical record. If these data were missing or if a patient had become lost to follow-up, we calculated costs on the basis of patients' average number of visits to the same PHC.

Income loss was estimated on the basis of the monthly income change reported in the baseline study. The monthly income change was calculated as the difference in income between that received before TB diagnosis and that received at the time of the interview. The monthly income loss was multiplied by the number of months patients had undergone TB treatment. Patients who earned an uncertain monthly income from jobs in the informal sector, such as taxi-bike drivers, often were unable to provide exact information on changes from one month to the next. To avoid underestimating the income loss of these patients, we used the human capital approach to estimate their income loss.[4] We collected the self-reported time that patients took to seek and receive healthcare and the hourly rate the patient working in the informal sector normally charged for his/her informal work. We used the following formula to obtain total income loss: return trip in minutes for a typical visit × patient's income loss per minute × the number of visits over the course of treatment.

Patients may quit treatment due to their actual or expected future financial burden. Some patients, may therefore not experience catastrophic costs at the time they quitted treatment, but would have experienced such costs if they had continued until treatment completion. For patients who were lost to follow-up, we therefore extrapolated the direct and indirect costs by multiplying their direct unit cost by the average number of visits of patients treated in the same PHC. To extrapolate their income loss, we multiplied their monthly income loss by the number of months in a standard period of full treatment.

In addition to TB-related costs, patients also reported their monthly household income. Per patient, we calculated annual household income in the year before he or she had been diagnosed with TB. We calculated total costs as a share of annual household income, which was displayed as a proportion (%). If the proportion exceeded a specific threshold, e.g., 30%, we defined this as catastrophic costs.[17]

Statistical analyses

First, we analyzed the association between catastrophic costs (as independent variable) and treatment adherence and treatment outcomes (as dependent variables) using generalized linear mixed models (GLMM) with a logit link function, generating crude odds ratios (cORs) for these associations. We used random effects to adjust for our cluster-sampling design (19 PHCs). To determine the threshold at which catastrophic costs affect treatment outcomes and adherence, we ran the analysis using various thresholds, i.e., 10%, 15%, 20%, 25%, 30%, and 35%. The threshold at which catastrophic costs were statistically significantly associated with treatment outcomes and treatment adherence was used for further analyses.

Next, we examined whether confounding had produced the association observed in the univariate analysis between catastrophic costs, treatment outcomes, and treatment adherence. To assess whether the effect of costs had been confounded by other variables, we decided *a priori* to include all potential confounders for which we had data (i.e., age, sex, district, education, previous TB treatment, initial sputum result, hospitalization, and adverse drug effect). To obtain adjusted ORs (aORs) and 95% CIs, the potential confounders were analyzed simultaneously in a multivariable analysis. Since catastrophic costs incorporate income in their calculation, we did not include

household income level, breadwinner, and job-loss variables as potential confounders in our multivariable analysis.

To assess the contribution of catastrophic costs to unsuccessful treatment outcomes in the population, we also estimated the population-attributable fraction (PAF) for our study population. This was calculated as $[P_{pop} \times (OR-1)] / [P_{pop} \times (OR-1) + 1]$, where P_{pop} was the proportion of exposed subjects in the entire study population, and OR was the odds ratio of catastrophic costs to unsuccessful treatment outcomes obtained from the multivariable analysis.

Poor treatment adherence in this study included patients who had been lost to follow-up and patients whose treatment period had been prolonged. As prolonged treatment may lead to higher direct and indirect costs (e.g. more healthcare visits, higher income loss), it may be the cause rather than the consequence of catastrophic costs. In our univariate and multivariable analyses, we therefore examined whether the association between catastrophic costs and treatment adherence was due to reverse causation. To do so, we simulated cost data for patients with a prolonged treatment period by adjusting their number of visits to the average number of visits of patients treated in the same PHC, and, on the basis of their expected end-of-treatment date, by the number of months they had lost income. After recalculating the costs, we compared (1) the incidence of catastrophic costs between the actual costs and recalculated costs, and (2) the effect of catastrophic costs on treatment outcomes. No such reverse effects were expected for patients who had been lost to follow-up, for patients whose treatment had failed, or for patients who had died, as these patients' TB treatment had not been prolonged.

All data were cleaned and analyzed using IBM SPSS 21.[18] Costs and income data were entered in Indonesian Rupiah (IDR) and were then converted to US Dollars (USD) using the average exchange rate for 2016 (USD 1 = IDR 13,389.41).[19]

Results

One year after patients had been interviewed, the medical records of 27 patients were missing and could not be tracked for reasons such as storage relocation, the renovation of a PHC building, and change of several persons in charge of the TB program in PHCs. Three patients had moved to other healthcare facilities. In our analyses, we included

252 (89.4%) of the 282 subjects who had been interviewed in 2016 and whose treatment outcome and adherence had been recorded in 2017. (Figure 1)

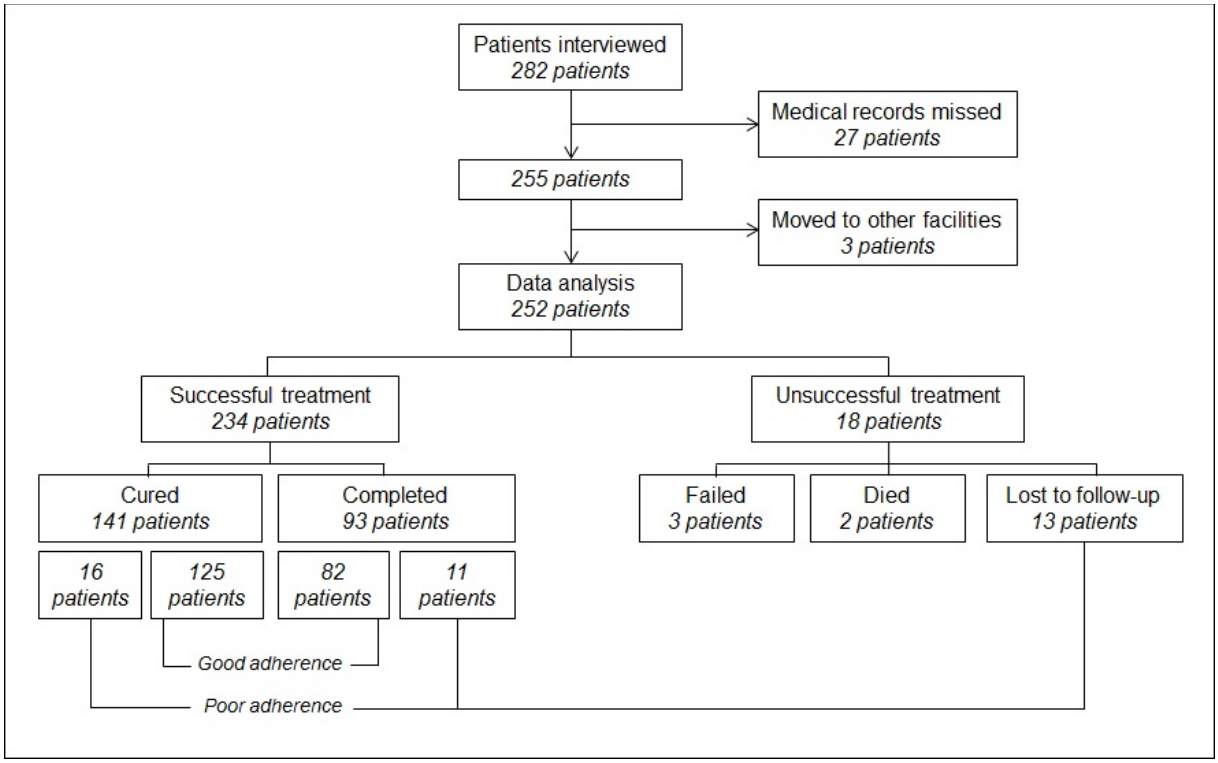

Figure 1 Number of subjects in one-year cohort

TB treatment had been successful for 234 patients (93%). Over half of all patients (n=141, 56%) were cured, as indicated from sputum smear conversion from a positive-smear to a negative-smear at the end of treatment, while 93 patients (37%) had completed the treatment without proof of smear conversion. Treatment had been unsuccessful in 18 patients (7%): three patients had failed, two patients had died, and 13 had been lost to follow-up. Most patients (n=207, 84%) had good treatment adherence. The treatment period had been prolonged in 27 patients (11%), and thirteen patients (5%) had been lost to follow-up. Treatment outcome had been successful in all patients with a prolonged treatment period.

Most patients lived in a poor household (61%), had an income-earning job (74%), had smear-positive TB (66%), and had undergone Category 1 TB treatment (the first-line treatment for susceptible TB patients who have not previously received TB treatment,

88%). (Table 2) The median of total costs incurred by the patients was USD 118 (IQR 455). The median of total costs as a share of annual household income was 9% (IQR 25%). The incidences of catastrophic costs were 46%, 38%, 33%, 26% and 22% at a threshold of 10%, 15%, 20%, 25%, and 30% of annual household income, respectively.

Table 2 Sociodemographic, clinical characteristics, and costs incurred by patients.

Characteristics	N %	Characteristics	N %
Sociodemographic	*n=252*	***Clinical characteristics***	
Age (years)		Category of treatment	
18-40	126 (50%)	Category 1	222 (88%)
41-60	93 (37%)	Category 2	30 (12%)
>60	33 (13%)	Result of initial sputum test	
Sex		Positive	167 (66%)
Male	135 (54%)	Negative	85 (34%)
Female	117 (46%)	Was hospitalized	
Household income level†		Yes	34 (13%)
Poor	153 (61%)	No	218 (87%)
Non-Poor	99 (39%)	Experienced adverse drug effect(s)	
Education level		Yes	4 (2%)
Low	87 (35%)	No	248 (98%)
Middle	154 (61%)		
High	11 (4%)		
Patient as breadwinner		***Costs***	
Yes	114 (45%)	Total costs, USD, median (IQR)	118 (455)
No	138 (55%)	Costs as a share of annual income, %, median (IQR)	9 (25)
Patient had earned money before diagnosis		Incidence of catastrophic costs	
Yes	187 (74%)	Threshold of 10%	117 (46%)
Fixed payment	83 (33%)	Threshold of 15%	97 (38%)
Uncertain	99 (39%)	Threshold of 20%	83 (33%)
Others	5 (2%)	Threshold of 25%	66 (26%)
No	65 (26%)	Threshold of 30%	55 (22%)
Experienced job loss‡	*n=187*	Threshold of 35%	44 (17%)
Yes	73 (39%)		
No	114 (61%)		

† *Household income was divided into two groups, poor and non-poor, on the basis of the World Bank definition that a household is as defined poor if the income per capita per day is ≤ USD 1.9.* ‡ *The percentages were calculated for those who had had an income-earning job before diagnosis.*

Our univariate analysis suggests that the odds of unsuccessful treatment outcomes were around 2 to 3 times higher for patients experiencing catastrophic costs compared with

patients not experiencing catastrophic costs at thresholds of 10%, 25% and 30% of annual household income. (Table 3) Nevertheless, the association was only statistically significant at the 0.05 level when using the 30% threshold (cOR 3.32, 95% CI 1.13-9.69, *P*=0.03).

Table 3 Associations between catastrophic costs and unsuccessful TB treatment outcome.

Catastrophic costs	Unsuccessful treatment†	cOR (95% CI)	*P*	aOR (95% CI)‡	*P*
Threshold of 10%					
Yes	12/117 (10.3)	2.60 (0.87-7.80)	0.09	2.59 (0.78-8.63)	0.12
No	6/135 (4.4)	1		1	
Threshold of 15%					
Yes	10/97 (10.3)	2.21 (0.76-6.38)	0.14	2.31 (0.72-7.47)	0.16
No	8/155 (5.2)	1		1	
Threshold of 20%					
Yes	8/83 (9.6)	1.74 (0.61-4.97)	0.30	1.80 (0.55-5.88)	0.33
No	10/169 (5.9)	1		1	
Threshold of 25%					
Yes	8/66 (12.1)	2.65 (0.92-7.69)	0.07	3.03 (0.89-10.31)	0.08
No	10/186 (5.4)	1		1	
Threshold of 30%					
Yes	8/55 (14.5)	3.32 (1.13-9.69)	0.03	3.86 (1.11-13.38)	0.03
No	10/197 (5.1)	1		1	
Threshold of 35%					
Yes	2/44 (4.5)	0.53 (0.11-2.51)	0.42	0.53 (0.10-2.86)	0.46
No	16/208 (7.7)	1		1	

†*Displayed as the number (and percentage) of patients with unsuccessful treatment among those who experienced or did not experience catastrophic costs.* ‡*Displaying aORs of unsuccessful treatment comparing patients with and without catastrophic costs after adjustment for all potential confounders for which we had information (i.e., age, sex, district, education, previous TB treatment, initial sputum result, hospitalization, and adverse drug effect).*

After adjustment for potential confounders in a multivariable analysis, catastrophic costs at a threshold of 30% remained statistically significantly associated with unsuccessful treatment outcomes. At this threshold, the odds of unsuccessful treatment outcomes were 3.86 times higher (95% CI 1.11-13.38, *P*=0.03) in patients who had experienced catastrophic costs than in patients who had not. Using this adjusted odds ratio, the PAF was 38.6%, meaning that 38.6% of unsuccessful treatment outcome cases

were attributable to catastrophic costs. At the 10%-25% thresholds, the pattern of associations was similar, with estimated odds ratios of around 2 to 3, but these associations were not statistically significant at conventional levels.

Our univariate analysis also suggests that catastrophic costs (at thresholds of 10%-25%) were associated with poor treatment adherence: the odds of poor adherence were approximately twice as high in patients who had experienced catastrophic costs as in those who had not. (Table 4) However, these findings were statistically significant at the 0.05 level only when using the 15% threshold. At this threshold, the odds of poor adherence among patients who had experienced catastrophic costs were 2.12 times higher (95% CI 1.01-4.45, *P*=0.046) than in those who had not. None of the other variables were statistically significantly associated with poor treatment adherence.

The association between catastrophic costs and poor treatment adherence was partly due to reverse causation. In other words, prolonged treatment had contributed to catastrophic costs. We evaluated the extent of reverse causation by conducting a simulation analysis for patients with prolonged treatment period. When we assumed that patients with extended treatment duration had finished their treatment on time, the strength of the association between catastrophic costs and treatment adherence fell, at the 15% threshold from cOR 2.12 to 1.87, at the 25% threshold from cOR 1.94 to 1.35, and at the 20% threshold from cOR 1.88 to 1.47. When also adjusting for potential confounders, catastrophic costs at the 10% and 15% thresholds were associated with a two-times higher odds of poor adherence compared to patients without catastrophic costs (aOR 2.11, 95% CI 0.97-4.59, *P*=0.059 and aOR 2.06, 95% CI 0.95-4.46, *P*=0.07). At other thresholds, we have no evidence of such an effect.

Table 4 Associations between catastrophic costs and poor treatment adherence in actual calculation and recalculation adjusted to normal treatment period.

Catastrophic costs	Univariate analysis						Multivariable analysis			
	Actual			Recalculation†			Actual		Recalculation	
	Poor adherence‡	cOR (95% CI)	*P*	Poor adherence‡	cOR (95% CI)	*P*	aOR (95% CI)§	*P*	aOR (95% CI)§	*P*
Threshold of 10%										
Yes	23/114 (20.2)	1.94 (0.94-4.02)	0.08	23/114 (20.2)	1.94 (0.94-4.02)	0.1	2.11 (0.97-4.59)	0.059	2.11 (0.97-4.59)	0.06
No	17/133 (12.8)	1		17/133 (12.8)	1		1		1	
Threshold of 15%										
Yes	20/94 (21.3)	2.12 (1.01-4.45)	0.05	19/93 (20.4)	1.87 (0.89-3.91)	0.1	2.35 (1.08-5.14)	0.03	2.06 (0.95-4.46)	0.07
No	20/153 (13.1)	1		21/154 (13.6)	1		1		1	
Threshold of 20%										
Yes	17/80 (21.3)	1.88 (0.90-3.94)	0.09	15/78 (19.2)	1.47 (0.70-3.09)	0.3	2.03 (0.93-4.42)	0.08	1.55 (0.71-3.38)	0.27
No	23/167 (13.8)	1		25/169 (14.8)	1		1		1	
Threshold of 25%										
Yes	14/63 (22.2)	1.94 (0.90-4.16)	0.09	11/60 (18.3)	1.35 (0.690-3.01)	0.5	2.08 (0.93-4.65)	0.08	1.40 (0.60-3.26)	0.44
No	26/184 (14.1)	1		29/187 (15.5)	1		1		1	
Threshold of 30%										
Yes	11/52 (21.2)	1.65 (0.73-3.70)	0.23	9/50 (18.0)	1.26 (0.54-2.97)	0.6	1.71 (0.73-4.00)	0.22	1.29 (0.53-3.15)	0.58
No	29/195 (14.9)	1		31/197 (15.7)	1		1		1	
Threshold of 35%										
Yes	8/44 (18.2)	1.27 (0.52-3.08)	0.59	5/41 (12.2)	1.75 (0.27-2.10)	0.6	1.35 (0.54-3.37)	0.52	0.80 (0.28-2.31)	0.68
No	32/203 (15.8)	1		35/206 (17.0)	1		1		1	

†*Recalculating costs if patient with prolonged treatment period finished their treatment on time,* ‡*Displayed as number (and percentage) of patients with poor treatment adherence among those who experienced or did not experience catastrophic costs,* §*Displaying aORs of poor comparing patients with and without catastrophic costs after adjustment for all potential confounders for which we had information (i.e., age, sex, district, education, previous TB treatment, initial sputum result, and hospitalization).*

Discussion

Our study shows that catastrophic costs can have a negative impact on treatment outcome. Generally, the odds of an unsuccessful treatment outcome were around two to four times higher among patients who experienced catastrophic costs compared with those who had not. While our findings were statistically significant at a threshold for catastrophic costs of 30%, there was an indication that this may also be the case at thresholds between 10% and 25%. The association between catastrophic costs and poor treatment adherence was more complex. Poor adherence can lead to higher costs. After adjustment for such reverse causation, we found that catastrophic costs at the 10% and 15% threshold were associated with an around two times higher odds of poor treatment adherence compared to patients who had not experienced such costs, with no effect at other thresholds.

While there is currently no agreement on the specific threshold of catastrophic costs for research and policy-making, various studies have defined this threshold as 20% of annual household income, as suggested by the WHO through their taskforce.[3, 16, 20] However, there is little evidence on whether use of this threshold accurately reflects the effect of catastrophic costs on treatment outcomes and treatment adherence. Until now, the only study which assessed the association between catastrophic costs and poor treatment outcome was the Peruvian study (2014) which it suggested a threshold of 20%.[5] The study included multidrug-resistant (MDR)-TB patients who incurred higher costs, and in that study, MDR-TB was found to be one of the determinants of poor outcomes. Different from the Peruvian study, our study focused on susceptible TB patients. We found that, at a 30% threshold, catastrophic costs lead to poor treatment outcomes, which, in our study, mostly consisted of patients who were lost to follow-up.

At a lower threshold (15%) catastrophic costs were associated with poor treatment adherence (prolonged treatment period or lost to follow-up). This association was due partly to reverse causation. Patients who did not adhere to their treatment course had to catch up with it, either under the orders of the PHC health staff (in order to comply with NTP program guidelines), or because they were self-motivated and wished to minimize the risk of recurrence. The additional visits needed to complete the full treatment course led to higher costs and greater income loss, which in some cases led to catastrophic

costs. At the same time, even after accounting for such reverse causation, catastrophic costs still negatively affected treatment adherence at thresholds of 10%-15%. Due to the size of our study and lack of statistical power, although there is indication of a similar effect at the thresholds of 20-30%, we need to be cautious to draw firm conclusion with respect to these levels.

With regard to future global policy, our study provides evidence that can inform a review of the threshold at which catastrophic costs should be measured. If these catastrophic costs are thought to affect patient adherence, the threshold of 15% of annual household income, might be considered to define catastrophic costs. When considering TB treatment outcomes, the threshold of 30% of annual household income, might be used to define catastrophic costs. Nevertheless, as also suggested by the WHO,[20] the threshold for defining catastrophic costs may vary between countries, and should be carefully assessed from one setting to the next.

This study is the first cohort study on TB-related catastrophic costs, treatment adherence, and treatment outcomes in Indonesia. Although we collected data from urban, suburban, and rural areas of Indonesia, all these areas were located on the island of Java, which is home to 60% of the Indonesian population. Our findings may not therefore apply directly to eastern Indonesia and to the country's other remote areas, where healthcare facilities are scarcer—a factor that may affect treatment outcomes and treatment adherence. Similarly, as our study was conducted only in PHCs, its findings may underestimate the costs of the treatment given by private providers (which are assumed to be higher), while simultaneously overestimating treatment adherence, which may be lower among patients who are treated by private providers.[21] It is also uncertain whether our findings will apply to TB high-burden countries in which TB service delivery is different. Finally, the precise effect estimates in our study remain uncertain due to the limited sample size of the study. While our study is the first to provide evidence for Indonesia on the effects of catastrophic costs on treatment outcomes and treatment adherence, and one of the very few studies that do so for TB high-burden countries more generally, larger studies are warranted.

We conclude that catastrophic costs negatively impacted TB treatment outcomes and TB adherence at the various thresholds of annual household income. This highlights the

need for TB control interventions to properly address both the clinical and socio-economic aspects of the disease.

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Ethics approval and consent to participation

Ethical clearance for this study was provided by the Ethical Committee at the Faculty of Medicine of Universitas Indonesia–Cipto Mangunkusumo Hospital, Jakarta Indonesia (No. 416/UN2.F1/ETIK/VI/2016). We provided written and oral explanations to selected TB patients before they decided to sign the informed-consent form.

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Chapter 6

Effect of financial support on reducing the incidence of catastrophic costs among tuberculosis-affected households in Indonesia: eight simulated scenarios

Ahmad Fuady,[1,2] Tanja A.J. Houweling,[1] Muchtaruddin Mansyur,[2] Erlina Burhan,[3] Jan Hendrik Richardus[1]

[1]Department of Public Health, Erasmus MC, University Medical Centre Rotterdam, Rotterdam, The Netherlands; [2]Department of Community Medicine, Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia; [3]Department of Respiratory and Pulmonology, Persahabatan Hospital – Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia

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Abstracts

Background:

The World Health Organization's End Tuberculosis Strategy states that no tuberculosis (TB)-affected households should endure catastrophic costs due to TB. To achieve this target, it is essential to provide adequate social protection. As only a few studies in many countries have evaluated social-protection programs to determine whether the target is being reached, we assessed the effect of financial support on reducing the incidence of catastrophic costs due to TB in Indonesia.

Methods:

From July to September 2016, we interviewed adult patients receiving treatment for TB in 19 primary health centres in urban, sub-urban and rural area of Indonesia, and those receiving multidrug-resistant (MDR) TB treatment in an Indonesian national referral hospital. Based on the need assessment, we developed eight scenarios for financial support. We assessed the effect of each simulated scenario by measuring reductions in the incidence of catastrophic costs.

Results:

We analysed data of 282 TB and 64 MDR-TB patients. The incidences of catastrophic costs in affected households were 36% and 83%, respectively. Patients' primary needs for social protection were financial support to cover costs related to income loss, transportation, and food supplements. The optimum scenario, in which financial support would be provided for these three items, would reduce the respective incidences of catastrophic costs in TB and MDR-TB-affected households to 11% and 23%. The patients experiencing catastrophic costs in this scenario would, however, have to pay high remaining costs (median of USD 910; interquartile range [IQR] 662) in the TB group, and USD 2613; [IQR 3442] in the MDR-TB group).

Conclusions:

Indonesia's current level of social protection is not sufficient to mitigate the socioeconomic impact of TB. Financial support for income loss, transportation costs, and food-supplement costs will substantially reduce the incidence of catastrophic costs, but financial support alone will not be sufficient to achieve the target of 0% TB-affected households facing catastrophic costs. This would require innovative social-protection policies and higher levels of domestic and external funding.

Background

Poverty is closely related to tuberculosis (TB), both as a risk and as an effect. People in low-income households not only have a higher risk of TB infection, but once they are infected, the high costs associated with diagnosis and treatment may reduce them to poverty.[1,2] Although almost all countries provide drugs free of charge to patients with susceptible TB and multidrug-resistant TB (MDR-TB), TB patients still face high direct non-medical costs such as those for travel, food, and nutritional supplements.[3-5] Indonesia has the world's third largest number of estimated TB cases with the incidence of 842 000 (95% Confidence Interval [CI] 767 000 – 919 000) cases. Despite its free TB services, our recent study revealed that the costs incurred during the treatment phase constituted more than three-quarters of the total costs.[6] These high costs can negatively affect treatment adherence, clinical outcomes, and drop-out rates, thereby further increasing future costs. The high costs also carry the risk of plunging TB patients and their families into poverty, or into even deeper poverty for those already living in poverty.[7-11]

In response to this socioeconomic burden, the World Health Organization's (WHO's) End TB Strategy aims by 2020 to reduce to zero the percentage of TB-affected families that face catastrophic costs. Catastrophic costs due to TB are defined as the total costs – i.e., all direct and indirect costs, including income loss — that exceed a specific threshold (e.g., 20%) of a household's annual incom.[12] One obvious option for attaining this target is by providing adequate social protection. In 2014, the Indonesian government started a national health insurance scheme that covers all the medical costs – including those of TB treatment – incurred in primary, secondary and tertiary healthcare. This scheme has substantially reduced direct medical costs. However, direct medical costs are not the only costs patients face in the trajectory from the pre-diagnostic phase to treatment completion.[4,13] In 2016, the previous study we conducted in Indonesia showed that total costs consisted largely of direct non-medical costs and income loss.[6] As these are not covered by the health insurance scheme, TB patients are still at a high risk of facing catastrophic costs. This highlights the importance of providing additional financial protection to cover direct non-medical costs and income loss.[13]

There are three approaches to delivering additional social protection.[14] The first is the TB-specific approach, which offers protection only to TB patients or TB-affected households, for example by providing food-supplements or travel vouchers to those undergoing TB treatment in health facilities that are linked to the network of the National Tuberculosis Program (NTP).[14,15] The second, the TB-inclusive approach, is a broader intervention in which TB patients or TB-affected households are one of the inclusion criteria in a social-protection program. The third, the TB-inclusive approach, involves protection policies that do not explicitly include TB patients or TB-affected families in their eligibility criteria but include TB risk-reduction strategies for groups at a high risk for TB infection, such as general cash transfers and premium-free national health insurance for people in poor households.

However, there is little evidence on the effectiveness of financial protection (including cash transfers) in reducing the incidence of catastrophic costs due to TB, particularly in TB high-burden countries (HBCs). Although recent studies have shown that cash transfers could defray the costs endured by TB-affected households,[15,16] the transfers in question were either given conditionally (on the basis of adherence to the intervention program), or were given on the basis of published national average cost data rather than of patients' actual needs. There is limited evidence on the effect of social-protection schemes that take account of patients' needs and preferences.[17]

In this study we therefore aimed to measure the socioeconomic impact of TB and MDR-TB (including the incidence of catastrophic costs), and to assess patients' perceived needs for social protection in Indonesia. Additionally, to assess the effects of financial support on the incidence of catastrophic costs due to TB and MDR-TB in poor and non-poor households, we developed and ran hypothetical scenarios in which patients were offered different combinations of financial support.

Methods

Study design

To measure the socioeconomic impacts of TB and the perceived needs for social protection, we interviewed TB and MDR-TB patients. For TB patients, we applied stratified clustered sampling in three districts of Java, one representing an urban area of Indonesia (Jakarta), one representing a suburban area (Depok), and one representing a rural area (Tasikmalaya). In each district, we randomly selected 5–8 primary health centres (PHCs) that were linked with the Indonesian NTP. Then, from July to September 2016, we selected consecutive TB patients consecutive TB patients as they registered at these PHCs. Assuming that the incidences of TB-affected household facing catastrophic costs were 20% (urban), 25% (suburban) and 30% (rural), assuming a 1:1:1 ratio of TB incidence in urban, suburban and rural district, and assuming a power of 0.80, we required a minimum of 90 TB patients who met the inclusion criteria in each district. We included adults aged 18 years or above who had been diagnosed with TB and had either received TB treatment for at least one month or had finished the treatment no more than one month previously. In this study, we focused on pulmonary TB and excluded extra-pulmonary TB patients because of potentially different seeking care pattern and costs. With regard to MDR-TB, we interviewed adult patients who had been diagnosed on the basis of GeneXpert® (Cepheid, Sunnyvale, CA, USA) or sputum culture and had been undergoing treatment for at least one month in Persahabatan Hospital, an MDR-TB referral hospital in Jakarta.

In both groups of patients, we assessed the following variables: the incidence of catastrophic costs, the socioeconomic impacts of TB or MDR-TB, and patients' perceived needs for social protection. On the basis of the needs assessment, we then developed several scenarios for financial support. In each scenario, we measured the reduction in the incidence of catastrophic costs after the hypothetical provision of financial support.

Socioeconomic impacts due to TB and MDR-TB

To measure the socioeconomic impacts of TB, we used the Tool to Estimate Patient Costs,[12,18] which we adapted to the Indonesian context, also translating it to Indonesian Bahasa. We recruited ten medical students and public health graduates as interviewers and trained them in the use of the adapted tool. The socioeconomic impacts we studied the incidence of TB-affected households facing catastrophic costs; patients' perception of the their TB or MDR-TB is having on their households' financial capacity expressed on a scale of 1–5, from no problem to a very serious problem; coping strategy (loaning money or selling property); job and income loss due to TB; and the proportional reduction in patients' and households' income. Patient and household income loss were calculated both in absolute terms (in United States dollars, USD) and in relative terms (percentage of loss of previous income).

As well as collecting information on all types of cost (i.e., direct medical costs, direct non-medical costs, and indirect costs) that had been incurred by the TB-affected households in the period between the pre-diagnostic phase and treatment completion, we also collected information on these households' annual income. Following the latest WHO protocol, we measured the incidence of catastrophic costs (defined as total direct and indirect costs) that exceeded 20% of each TB-affected household's annual income [6,12]. Details of the methods we used to calculate the incidence of catastrophic costs due to TB are provided in our previous study.[6]

Perceived needs for social protection

To assess patients' knowledge of social protection and their perceived needs for additional social protection, we added three questions at the end of the adapted tool: "Have you ever heard of social protection?", followed by an open question: "If yes, what is social protection? Can you explain it?"

Patients' answers were grouped according to six types of social protection: general government aid for the poor; government aid for healthcare; direct government aid (general cash transfer); government aid for education: government aid for transportation costs; and other government aid. A patient's

inability to name or explain any type of social protection was defined as 'did not know'. These questions were important to our ability to assess patients' knowledge before questioning them on their needs for social protection. After obtaining the patients' answers, the interviewers explained the definition of social protection and gave examples of several types of social-protection scheme.[19] They then asked the patients whether they needed any social protection, or additional protection if they already receiving.

Patients who stated that they needed social protection were asked to choose one cost item they wanted to be covered, and its value in Indonesian Rupiahs (IDR). These items comprised consultation fee per visit, transportation costs per visit, food costs per visit, drug costs per month, income loss per month, and food-supplement costs per month. Food-supplement costs were defined as a patient's monthly spending on nutritional or food supplements such as vitamins, fruits, milk, meats, or other nutritional supplements that were consumed either with or without a doctor's TB-related recommendation [19]. After the patients' answers had been obtained, the cost items that needed to be covered were listed in order of priority (from those that had been indicated most to those that had been indicated least). The median (interquartile range [IQR]) of these cost items was then calculated. In the scenarios that we developed, we then used the median values of these cost items as the value of financial support.

Effects of financial support

On the basis of the needs assessment, we selected the three cost items that patients chose, and then developed several hypothetical scenarios for financial support. These comprised the following: no provision of a cash transfer (baseline); the provision of a cash transfer to cover a single cost item (i.e., income loss, transportation costs, or food-supplementation); and the provision of a cash transfer to cover a combination of two or three cost items. In total, we developed eight such scenarios. As well as the baseline scenario (no cash transfers; Scenario I), we formulated seven hypothetical cash-transfer scenarios for the following: (II) transportation costs for all patients, (III) food-supplement costs for all patients, (IV) income loss for patients who had lost their jobs, (V) income loss for patients who lost their income whether or not they had lost their jobs, (VI) a

combination of transportation costs and income loss, (VII) a combination of food-supplement costs and income loss, and (VIII) a combination of transportation costs, food-supplement costs, and income loss.

We simulated the hypothetical scenarios in the people who had been included in this study, assuming that the cash transfers had been made after patients had started TB or MDR-TB treatment. The value of the cash transfer (CT) for specific cost items was extrapolated to a complete treatment period (denoted $CT_{i}^{CI,h}$ in which CI identifies a specific cost item, i identifies the patient, and h identifies his/her household). For transportation costs, the total cash transfer was calculated by multiplying CT by the number of PHC or hospital visits during the intensive phase V_{i}^{IP} and continuation phase V_{i}^{CP} until the expected end date of treatment. For income loss and food-supplement costs, the total value of the cash transfer was calculated by multiplying CT by the duration (in months) of the patients' complete treatment, M.

Box 1 Cash-transfers formula

$$Total\ CT\ transportation = \sum_{i=1}^{n}\left((CT_i^{CI,h}\, x\, V_i^{IP}) + (CT_i^{CI,h}\, x\, V_i^{CP})\right)$$

$$Total\ CT\ income\ loss = \sum_{i=1}^{n}\left(CT_i^{CI,h}\, x\, M\right)$$

$$Total\ CT\ food\ supplement = \sum_{i=1}^{n}\left(CT_i^{CI,h}\, x\, M\right)$$

Total costs were defined as the sum of all types of cost, including out-of-pocket payments (*OOPs*) for medical diagnosis and treatment (*OOPM*); OOPs for non-medical expenditures (*OOPNM*); and patients' and guardians' income losses (*IN*). After calculating the total simulated costs after the cash transfer (total costs for TB-related services minus the total cash transfer), we estimated the incidence of catastrophic costs after the cash transfer in each scenario. To define

catastrophic costs, we used the threshold of 20% of annual household income (denoted τ^{TB}).

$$I_{NTP}^{TB} = \frac{1}{n_{NTP}^{TB}} \sum_{i=1}^{n_{NTP}^{TB}} 1\left(\frac{\sum_{j=1}^{n_{-i}} \left((OOPM_{j}^{TB,h} + OOPNM_{j}^{TB,h} + IN_{j}^{TB,h}) - Total\ CT \right)}{y_{i}^{h}} > \tau^{TB} \right)$$

TB patient is denoted as j while the household is denoted as i.[12] If there is more than one TB patient in one household, costs for all patient within the household will be collected or estimated. Although the hypothetical scenarios were based on the optimistic assumption that all patients would receive 100% of the potential cash transfer, some intervention studies have shown that 10–36% of targeted beneficiaries did not receive complete financial support.[15,20,21] To obtain valid estimates of the effect of the cash transfers, we ran sensitivity analyses that assumed patients would receive 60%, 70%, 80%, and 90% of the potential cash transfer.

Data analysis

Data were entered into EpiInfo™ for Windows (Centers for Disease Control and Prevention (CDC), Atlanta, GA, USA) and Microsoft® Office Excel 2010 (Microsoft). For data cleaning and analysis, we used IBM SPSS Statistics for Windows, Version 21 (IBM Corp., Armonk, NY, USA). Categorical variables were displayed as numbers (*n*) and proportions (%). All costs, incomes, and values of financial support for each cost item were collected in IDR and then converted to US Dollars (USD) using the average exchange rate by the World Bank for 2016 (USD 1 = IDR 13 389.41).[22] These numerical data were abnormally distributed and therefore displayed as median values (IQRs).

We compared the socioeconomic impacts, the perceived needs for social protection, and the effect of financial support between poor and non-poor households. A poor household was defined as a household earning below USD 1.9 per capita per day.[23] To compare the socioeconomic impacts due to TB and the effects of financial support between poor and non-poor TB-affected households, we applied generalized linear mixed models with random effects to

adjust for a cluster sampling design (19 PHCs). For the MDR-TB group, we used chi-square, Fisher, and Mann-Whitney tests to analyze the impacts between poor and non-poor households. To compare the effects of financial support between scenarios, we used McNemar tests with stratification for cluster sampling for TB (19 PHCs), and without stratification for MDR-TB. For each scenario we used bootstrapping for internal validations of the incidence of catastrophic costs after cash transfer and the average budget per patient required in each scenario (N=1000). The difference was considered statistically significant if P-value was below than 0.05.

Ethical statement

Ethical clearances for this study were obtained from the Ethical Committee at the Faculty of Medicine of Universitas Indonesia–Cipto Mangunkusumo Hospital, Jakarta Indonesia (No. 416/UN2.F1/ETIK/VI/2016) and the Ethical Committee at Persahabatan Hospital, Jakarta, Indonesia (No. DL.01.03/II.3/3817/2016). We provided written and oral explanations to patients before their decision to sign the informed-consent form.

Results

In total, we analysed the data for 282 TB and 64 MDR-TB patients. The details of patients' characteristics are provided in our previous study on catastrophic costs due to TB.[6]

Socioeconomic impacts of TB or MDR-TB

The incidence of catastrophic costs due to TB was high, and was significantly higher among MDR-TB-affected households (83%) than among TB-affected ones (36%, $P < 0.001$). Most MDR-TB patients (78%) perceived that TB created moderate to severe problems for the financial capacity of their household. This proportion was lower among TB patients (48%; *P-value* for the difference between MDR-TB and TB patients = 0.009). These financial problems led more

MDR-TB patients than TB patients to loan money (50% vs 32%, $P = 0.042$) and to sell property (28% vs 12%, $P = 0.008$) (see Table 1).

Among TB-affected households, poor households suffered much more than non-poor households: they had a higher incidence of catastrophic costs (43% vs 25%, $P = 0.006$) and a higher proportion of patients who loaned money (38% vs 22%, $P = 0.014$) and sold property (15% vs 6%, $P = 0.029$). A more substantial proportion also suffered from moderate to severe financial problems (54% vs 38%, $P = 0.030$). Conversely, in MDR-TB-affected households, these economic impacts did not differ significantly between poor and non-poor households.

Before diagnosis, more than three-quarters of all patients had an income-earning job. Among them, TB and MDR-TB caused a high rate of job loss, which was higher in MDR-TB patients than in TB patients (69% vs 32%, $P = 0.001$). In addition to job loss, TB also caused income loss: although some patients maintained their jobs after diagnosis, their income decreased. The proportion of patients who lost income was much higher than the proportion who experienced job loss, and was higher among MDR-TB patients than among TB patients (86% vs 61%, $P = 0.011$).

Table 1 Socioeconomic impact on patients due to TB

Socioeconomic impacts	TB				MDR-TB				
	Total (%)	Poor (%)	Non Poor (%)	P*	Total (%)	Poor (%)	Non Poor (%)	P*	P**
	n = 282	*n* = 175	*n* = 107		*n* = 64	*n* = 23	*n* = 41		
Household experiencing catastrophic costs	102 (36)	75 (43)	27 (25)	0.006	53 (83)	19 (83)	34 (83)	1.000	< 0.001
Perceived impact on financial capacity[a]									
No problem	96 (34)	51 (29)	45 (42)		5 (8)	0 (0)	5 (12)		
Slight problem	50 (18)	29 (17)	21 (20)		9 (14)	3 (13)	6 (15)		
Moderate problem	58 (21)	42 (24)	16 (15)		13 (20)	5 (22)	8 (20)		
Serious problem	48 (17)	32 (18)	16 (15)		20 (31)	7 (30)	13 (32)		
Severe problem	30 (11)	21 (12)	9 (8)		17 (27)	8 (35)	9 (22)		
Perceived impact on financial capacity[b]									
No problem to slight problem	146 (52)	80 (46)	66 (62)	0.030	14 (22)	3 (13)	11 (27)	0.201	0.009
Moderate to severe problem	136 (48)	95 (54)	41 (38)		50 (78)	20 (87)	30 (73)		
Coping strategy									
Loaning money	91 (32)	67 (38)	24 (22)	0.014	32 (50)	14 (61)	18 (44)	0.193	0.042
Selling property	33 (12)	27 (15)	6 (6)	0.029	18 (28)	5 (22)	13 (32)	0.395	0.008
Having an income-earning job	201 (71)	119 (68)	82 (77)	0.139	49 (77)	17 (74)	32 (78)	0.708	0.477
	n = 201	*n* = 119	*n* = 82		*n* = 201	*n* = 119	*n* = 82		
Impact on job and income									
Job loss	64 (32)	38 (32)	26 (32)	0.801	34 (69)	10 (59)	24 (75)	0.242	0.001
Sick leave	6 (3)	4 (3)	2 (2)	1.000	2 (4)	1 (6)	1 (3)	1.000	0.657
Income loss	122 (61)	78 (66)	44 (54)	0.117	42 (86)	12 (71)	30 (94)	0.041	0.011
% reduction in median (IQR) of patient's previous income, %[c]	40 (100)	50 (0)	18 (100)	0.197	100 (54)	100 (100)	100 (0)	0.091	0.002
% reduction in median (IQR) of household's previous income, %[c]	20 (55)	29 (67)	8 (44)	0.250	40 (38)	27 (72)	42 (27)	0.924	0.299

*[a]Perceived impacts in five categories: no problem, slight problem, moderate problem, serious problem, and severe problem, [b] Perceived impacts in combined categories: no problem to slight problem and moderate to severe problem, [c] Calculated for patients reporting income loss. * P-values indicate the statistical significance of differences between poor and non-poor households. ** P-values indicate the statistical significance of differences between TB and MDR-TB groups.*

The extent of income loss among patients who had had an income-earning job before diagnosis was substantial in both relative and absolute terms. Relative income loss was very high among MDR-TB patients (median of 100% [IQR 54%]) and was significantly higher than among TB patients (P = 0.002). Patient's income loss subsequently reduced household income (median of 40% [IQR 38%] in MDR-TB and 20% [IQR 55%] in TB patients, P = 0.299). While the point estimates of relative income loss suggest that the loss was much higher among poor TB patients than among non-poor TB ones, the difference was not significantly different.

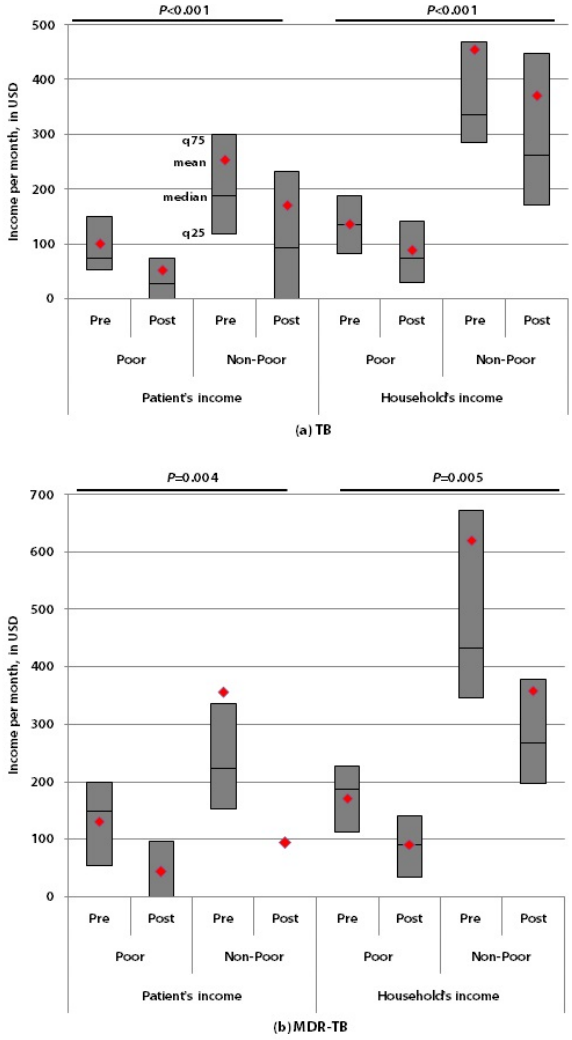

Figure 1 Patient and household income in (a) TB and (b) MDR-TB-affected households.

Pre: income before TB diagnosis. Post: income after TB diagnosis. P-values above the bar charts indicates the statistical significance of the absolute difference in income loss between poor and non-poor households. Per bar, red rhombs indicate the mean value of income, upper horizontal lines indicate the q75 value, middle horizontal lines indicate the median value, and lower horizontal lines indicate the q25 value.

Absolute loss (in USD) in patient's monthly income was higher in non-poor households than in poor households, both in the TB (*P*-value for difference poor and non-poor: < 0.001) and MDR-TB group ($P = 0.004$) (Figure 1). Household income loss was also greater in non-poor households than in poor households, both in the TB ($P < 0.001$) and MDR-TB group ($P = 0.005$).

Patients' perceived needs for social protection

Most patients (84% of TB patients and 80% of MDR-TB patients) did not know existing social-protection schemes (Table 2). Even 81% of patients who had health insurance did not know what social protection was and were unable to name existing social-protection schemes. Knowledge of existing schemes did not differ significantly between TB and MDR-TB patients ($P = 0.794$), or between those with and without health insurance ($P = 0.112$). The forms of social protection that were most commonly named by those who knew of such schemes were government aid for poor people (in general) and government aid for healthcare.

Table 2 TB and MDR-TB patients' knowledge of social-protection schemes

Knowledge of existing social-protection scheme	Type of TB		*P*	Having insurance		*P*
	TB n (%)	MDR-TB n (%)		Yes n (%)	No n (%)	
Did not know what social protection was	236 (84)	51 (80)	0.794	187 (81)	100 (88)	0.112
Knew and could name the following social-protection schemes:	46 (16)	13 (20)		45 (19)	14 (12)	
Government aid for poor people (in general)	19 (7)	4 (6)		19 (8)	4 (4)	
Government aid for healthcare	13 (5)	2 (3)		11 (5)	4 (4)	
Direct government aid, cash transfer [a]	11 (4)	1 (2)		9 (4)	3 (3)	
Government aid for transportation costs	0 (0)	3 (5)		3 (1)	0 (0)	
Government aid for education	1 (0)	2 (3)		2 (1)	1 (1)	
Other government aid	0 (0)	1 (2)		0 (0)	1 (1)	

[a] known as *Bantuan Langsung Tunai* in Indonesian Bahasa

After it had been explained what social protection was, most patients perceived that they needed social protection. The perceived need was higher among MDR-TB patients than among TB patients (95% vs 73%, $P = 0.004$). Perceived need did not differ significantly between poor and non-poor patients in either the TB group (75% vs 70%, $P = 0.334$) or the MDR-TB group (100% vs 93%, $P = 0.547$).

TB and MDR-TB patients all indicated that the three cost items that most needed to be covered were income loss (indicated by 24% of TB patients and 34% of MDR-TB patients); transportation costs (19% and 42%); and costs for food supplements (15% and 8%) (Table 3). Patients who reported that they required financial support were asked about the value of support they needed. As the wide interquartile ranges show, the value of financial support required varied strongly per cost item. MDR-TB patients perceived a need for a much higher value of financial support per month for their income loss than TB patients (median of USD 205 [IQR 121] vs USD 75 (IQR 112), $P < 0.001$). However, with regard to transportation costs per treatment visit and food-supplement costs per month, the values of the financial support required did not differ between the groups. Among MDR-TB patients, the values of the financial support needed did not differ between poor and non-poor households. But in the TB group, non-poor households perceived a need for a slightly higher value of financial support for income loss, transportation, and food supplements ($P < 0.001$).

The needs perceived by patients who indicated that they needed financial support were compared with the actual costs incurred by all patients. For income loss, we compared the value of perceived needs with the actual income loss suffered by (a) patients who had experienced job loss after diagnosis and (b) patients who had experienced any income loss due to TB regardless of whether or not they had experienced job loss. Among TB patients, the median value of the perceived need for financial support to cover income loss was lower than the actual costs. Conversely, among MDR-TB patients, the perceived value of financial support was higher than their actual costs. For transportation and food-supplement costs, we compared the value of perceived needs with the costs actually incurred by all patients. The values of financial support needed for these two cost items among patients who expressed the need for support were higher than the actual median costs among all patients.

Table 3 Perceived needs for financial support for each cost item and their actual costs, median (IQR), in USD.

Cost items	Perceived needs[a]							Actual costs[b]		
	Total		Poor		Non-Poor			Total	Poor	Non-Poor
	n (%)	Median (IQR)	*n* (%)	Median (IQR)	*n* (%)	Median (IQR)	*P***	Median (IQR)	Median (IQR)	Median (IQR)
TB	*n* = 282		*n* = 175		*n* = 107					
Income loss, *per month*	68 (24)	75 (112)	40 (23)	75 (112)	28 (26)	75 (131)	< 0.001	86 (127)[c]	75 (77)[c]	149 (185)[c]
								75 (112)[d]	61 (87)[d]	142 (174)[d]
Transportation, *per visit*	54 (19)	4 (5)	42 (24)	2 (2)	12 (11)	7 (17)	< 0.001	0 (1)	1 (1)	0 (0)
Food-supplement, *per month*	42 (15)	22 (37)	24 (14)	22 (21)	18 (17)	34 (60)	< 0.001	2 (11)	1 (9)	3 (15)
Consultation, *per visit*	11 (4)	13 (19)	6 (3)	10 (21)	5 (5)	22 (26)	< 0.001	0 (0)	0 (0)	0 (0)
Drugs, *per month*	11 (4)	15 (33)	8 (5)	10 (15)	3 (3)	37 (4)	0.188	0 (0)	0 (0)	0 (0)
Food, *per visit*	3 (1)	4 (3)	2 (1)	2 (3)	1 (1)	7 (0)	0.477	0 (0)	0 (0)	0 (0)
Other disease(s), *per visit*	1 (0)	7 (0)	1 (1)	7 (0)	0 (0)	N/A	N/A	N/A[e]	N/A[e]	N/A[e]
Guardian, *per visit*	1 (0)	7 (0)	1 (1)	7 (0)	0 (0)	N/A	N/A	0 (0)	0 (0)	0 (0)
MDR-TB	*n* = 64		*n* = 23		*n* = 41					
Income loss, *per month*	22 (34)	205 (121)	6 (26)	176 (80)	16 (39)	224 (174)	0.367	183 (105)[c]	149 (191)[c]	205 (149)[c]
								176 (114)[d]	123 (180)[d]	183 (149)[d]
Transportation, *per visit*	27 (42)	4 (11)	10 (43)	3 (13)	17 (41)	4 (8)	0.223	1 (2)	1 (2)	1 (2)
Food-supplements, *per month*	5 (8)	22 (34)	3 (13)	30 (26)	2 (5)	19 (7)	0.2	15 (29)	15 (30)	15 (24)
Consultation, *per visit*	0 (0)	N/A	0 (0)	N/A	0 (0)	N/A	N/A	0 (0)	0 (0)	0 (0)
Drug, *per month*	0 (0)	N/A	0 (0)	N/A	0 (0)	N/A	N/A	0 (0)	0 (0)	0 (0)
Food, *per visit*	3 (5)	1 (1)	2 (9)	1 (0)	1 (2)	2 (0)	1	1 (1)	1 (1)	1 (1)
Other disease(s), *per visit*	0 (0)	N/A	0 (0)	N/A	0 (0)	N/A	N/A	N/A[e]	N/A[e]	N/A[e]
Guardian, *per visit*	1 (2)	7 (0)	0 (0)	N/A	1 (2)	7 (0)	N/A	0 (0)	0 (0)	0 (0)

*[a] The value of perceived needs for financial support were calculated only on the basis of information provided by those who indicated that they need financial support for each specific cost item. [b] Actual costs except for income loss were calculated on the basis of information from all patients; [c] Actual costs for income loss were calculated on the basis of information from patients who experienced job loss after diagnosis; [d] Actual costs for income loss were calculated on the basis of information from patients who had experienced personal income loss regardless of whether or not they had experienced job loss after diagnosis; N/A, not applicable; [e] During the interview, no specific question was asked on actual costs for other diseases; **P-values indicate the statistical significance of differences regarding the value of perceived needs between poor and non-poor households per cost item.*

Effect of financial support on the incidence of catastrophic costs

In our simulated scenarios, we used the median values of the financial support required (see Table 3) to determine the value of cash transfers. The value of the cash transfer for transportation costs used in the simulations was USD 4 per visit. Due to differences in the number of visits per month, this suggests that the hypothetical monthly transfer for transportation costs would vary according to treatment regimen and treatment phase (intensive and continuation phase). For TB patients undergoing Category I treatment, the average number of visits was 4 visit per month during intensive phase and one visit per month during continuation phase. These resulted in the average value of the monthly cash transfer of USD 16 in the intensive phase and USD 4 in the continuation phase. For TB patients undergoing Category II treatment, with daily visit during intensive phase, the average value of the monthly cash transfer would be USD 120 in the intensive phase and USD 4 in the continuation phase. For MDR-TB patients, the average value of the monthly cash transfer for transportation would be USD 120 in both the intensive and continuation phases. The value of the cash transfer used in the simulations for food supplements was USD 22 per month, both for TB and MDR-TB patients. For income loss, the value of the cash transfer used in the simulations was USD 75 per month for TB patients and USD 205 per month for MDR-TB patients.

If TB-affected households were given support for transportation, food supplements and income loss (Scenario VIII), the incidence of catastrophic costs would be reduced by 25 percentage points, from 36% to 11% (Table 4). This scenario would have the greatest effects on reducing the incidence of catastrophic costs than any other scenario, reducing it by 17 percentage points if patients received only 60% of the potential cash transfer (Annex F). In this scenario, total median costs for TB patients would be reduced from USD 133 (IQR 522) to USD 0 (IQR 106) (results not reported in the table). Even so, catastrophic costs would still be faced by 11% of TB-affected households (95% confidence interval [*CI*] 8–15%). Among TB patients who still faced catastrophic costs after cash transfer, the total median costs would be reduced from USD 1527 (IQR 1023) to USD 910 (IQR 662).

Although having lower effects than Scenario VIII, cash-transfer modalities for two cost items (Scenarios VI and VII) would substantially reduce the incidence of catastrophic costs: between these two scenarios, there was no significant difference (Annex G). Of the cash-transfer modalities that would provide support for one cost item, Scenario V

would provide the most substantial effect. Other modalities of providing support for one cost item (Scenarios II-IV) would provide much smaller effects than Scenario VIII ($P < 0.001$). Between Scenarios II-IV, there were no significant differences.

Table 4 The incidence of catastrophic costs in eight hypothetical scenarios

	Simulated hypothetical scenario	Incidence of catastrophic costs	Average budget per patient for full duration of treatment, in USD
		% (95% *CI*)	Mean (95% *CI*)
TB			
I	Baseline (no cash transfer)	36 (31–42)	-
II	Transportation costs	28 (23–33)	114 (100–127)
III	Food-supplement costs	26 (21–30)	143 (141–145)
IV	Income loss[a]	26 (21–30)	110 (88–134)
V	Income loss[b]	17 (13–21)	210 (183–236)
VI	Transportation costs and income loss	17 (13–22)	224 (197–253)
VII	Food-supplement costs and income loss	16 (12–20)	253 (231–278)
VIII	Transportation, food supplement, and income loss	11 (8–15)	367 (338–398)
MDR-TB			
I	Baseline (no cash transfer)	83 (73–92)	-
II	Transportation costs	59 (47–71)	1337 (1327–1344)
III	Food-supplement costs	77 (65–87)	269 (269–269)
IV	Income loss[a]	58 (46–70)	1309 (1010–1617)
V	Income loss[b]	52 (39–65)	1617 (1338–1899)
VI	Transportation costs and income loss	28 (18–40)	2647 (2351–2958)
VII	Food-supplement costs and income loss	53 (41–66)	1578 (1279–1886)
VIII	Transportation, food supplement, and income loss	23 (13–35)	2916 (2620–3227)

[a]The hypothetical cash transfer was assumed to have been delivered to TB patients who had experienced job loss, [b]The hypothetical cash transfer was assumed to have been delivered to TB patients who had experienced any income loss regardless of whether or not they had experienced job loss.

In the MDR-TB group, cash transfers for transportation, food supplements and income loss (Scenario VIII) would reduce the incidence of catastrophic costs by 60 percentage points, from 83% to 23%. Of all the scenarios, Scenario VIII would have the greatest effect on reducing the incidence of catastrophic costs. Under Scenario VIII, median total costs for MDR-TB patients would decrease from USD 2804 (IQR 3317) to USD 0 (IQR 801). Twenty-three percent of MDR-TB-affected households would nonetheless face catastrophic costs after the transfer (95% *CI*: 13–35%). Under the same scenario,

median total costs for MDR-TB patients who still faced catastrophic costs after cash transfer would be reduced from USD 5606 (IQR 4430) to USD 2613 (IQR 3442).

Using the above cash-transfer values for each scenario, we estimated the average budget required per patient for the full duration of treatment under a social-protection program (Table 4, Figure 3) Scenario VIII would produce the most significant effect, but would also require the highest average budget per patient. For the MDR-TB group, the effect and the average budget of Scenario VI were only slightly smaller than those of Scenario VIII. Other scenarios would produce a much lower effect for a much lower average budget.

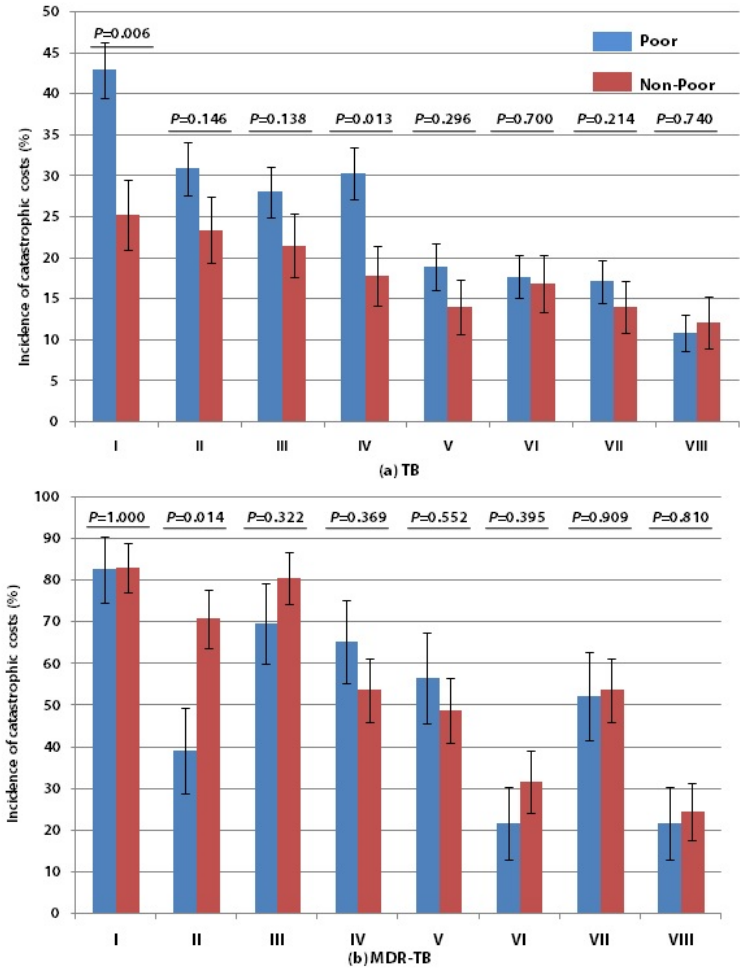

Figure 2 The incidence of catastrophic costs in poor and non-poor households in (a) TB and (b) MDR-TB-affected households. P-values indicate the differences per scenario between poor and non-poor households.

In the TB group, cash transfers would reduce the incidence of catastrophic costs to a much greater extent in poor households than in non-poor households (Figure 2). In Scenarios V-VIII, the gap between poor and non-poor households would disappear. A

sensitivity analysis showed that the gap would also disappear under Scenarios V-VIII if patients received only 60–90% of the cash transfers (Annex H, Annex I).

In the MDR-TB group, the incidence of catastrophic costs at baseline was equally high in the poor and non-poor households. With most scenarios, the impact was similar for poor and non-poor MDR-TB households. Only cash transfers for transportation costs (Scenario II) would produce a significantly lower incidence of catastrophic costs among poor households than among non-poor ones.

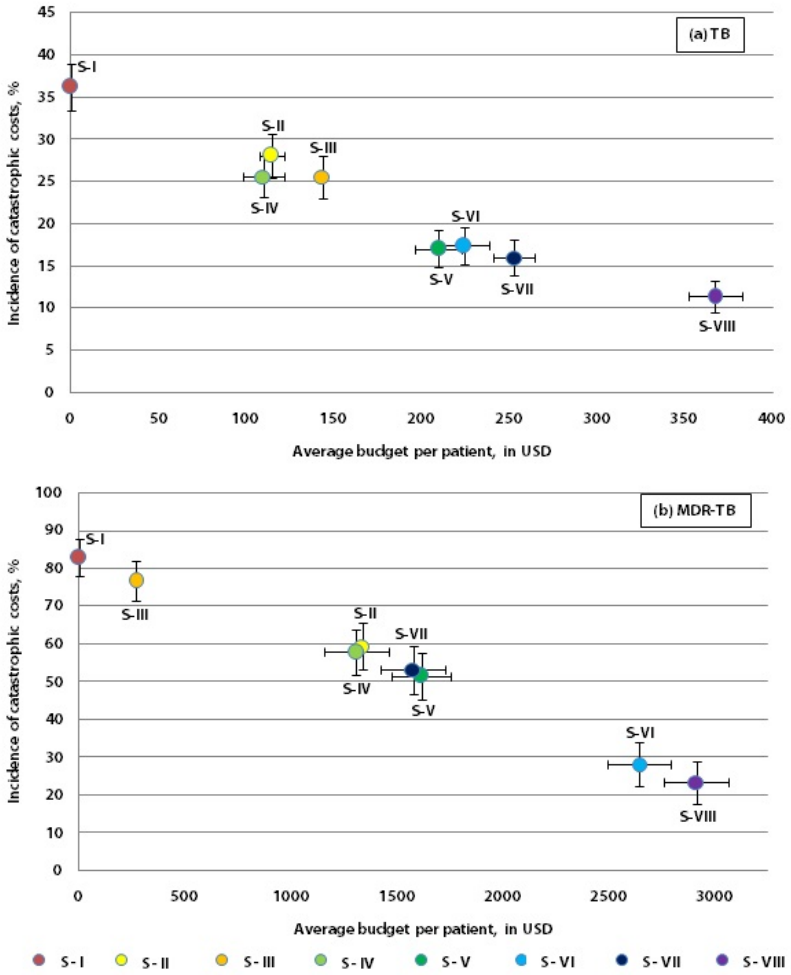

Figure 3 The remaining incidence of catastrophic costs and the average budget per patient for each scenario in (a) the TB group and (b) the MDR-TB group. Vertical lines in each colored circle are standard errors of the incidence of catastrophic costs. Horizontal lines in each colored circle are standard errors of the average budget per patient.

Discussion

Our results suggest that current levels of social protection in Indonesia are not enough to mitigate the socioeconomic impacts of TB, which include a high incidence of catastrophic costs, high rates of job and income loss, and a high proportion of patients who have to borrow money and sell their property. Due to these enormous impacts, TB patients urgently need social protection, mainly to cover the three costs they had indicated as most important: income loss, transportation costs, and food-supplement costs. In our simulations, the incidences of catastrophic costs were substantially reduced by a hypothetical scenario (Scenario VIII) that provided financial support for these three cost items. Nevertheless, a financial support system in which patients received fixed amounts of money for income loss, transport and food-supplement costs would not be able to reduce the incidence of catastrophic costs to zero percent, the target set by the WHO.

Our findings suggest that future policies should not rely on cash transfers for only one cost item. Although cash transfers to cover patient income loss can make a substantial contribution to reducing catastrophic costs, a single cash transfer of the sort examined in our study would not be enough to eliminate catastrophic costs. The existing types of support that patients may currently receive are equally inadequate; these mainly cover direct non-medical costs, such as food or nutritional supplement packages and travel vouchers from either government or international donors.[21,24,25] The impacts of financial support would be greater if cash transfers were provided for a combination of income loss, travel costs, and food-supplement costs.

Despite their substantial impact on reducing catastrophic costs, the cash transfers in our scenarios would not be enough to achieve the WHO's target of zero percent of households facing catastrophic costs. This failure is likely to be due to the high variability of costs between patients, and particularly of the cost due to income loss, which was the greatest component of the total costs incurred due to TB. Actual monthly income losses were also higher than the cash transfers simulated in our hypothetical scenarios. For example, while the transfer was set at USD 75 per month, actual median monthly income loss among TB patients who experienced job loss was USD 75 (IQR 77) for poor patients, and USD 149 (IQR 185) for non-poor patients.

As actual costs and the perceived needs for financial support vary greatly between patients, it is difficult to determine the value of any cash transfer to be delivered. We based the value of cash transfers on the median value of patients' perceived needs. Although the median value of cash transfer to cover transportation and food-supplement costs was higher than the median value of their actual costs, the actual value of transport and food supplements latter was sometimes higher than the cash transfer. The transfer in these cases did not cover the actual costs. However, the cash transfers simulated in our study would increase the NTP budget per capita by between approximately 46% (Scenario II) and 148% (Scenario VIII) for TB patients, and by between approximately 8% (Scenario II) and 20% (Scenario VIII) for MDR-TB patients.[26] While increasing the value of the cash transfers might be effective in terms of further reducing catastrophic costs, its affordability and sustainability should be carefully considered.

A way of reducing the incidence of catastrophic costs more effectively might be to target the financial support to those patients most likely to experience catastrophic expenditures. The targeting system could differ between settings, and could use various criteria to identify patients who need financial support.[14] Such criteria might include the determinants of catastrophic costs, such as household poverty level, job status before and after diagnosis, breadwinner status in the family, having had previous TB treatment, and experiencing adverse effects.[6] The disadvantages of such an approach would include the risks of greater stigmatization and of the greater bureaucracy needed to manage the targeting system, and may also prompt patients to pretend to remain sick in order to keep their entitlement to financial support.[14,24]

Our findings stress that the WHO's target of eliminating the incidence of catastrophic costs requires innovations in social-protection programs. If this objective is to be attained, a combination of strategies will be required to reduce the costs patients incur in the trajectory between the pre-diagnostic phase and the end of treatment. To reduce medical costs in the pre-diagnostic and diagnostic phases, TB service delivery under the NTP – which currently provides free TB treatment in NTP-linked health services only after diagnosis – should be fully integrated into the national health insurance scheme. In turn, such integration would speed up diagnostic procedures and improve access to TB treatment, possibly reducing transport costs and potentially even income loss. However, as the proportion of costs incurred in this phase is much smaller than the proportion of costs in the treatment phase,[6] the strategy would have limited impact on

total cost reduction. The strategy should therefore be combined with strategies for preventing socioeconomic impacts in the treatment phase of TB.

Since income loss was the greatest cost in the treatment phase, income loss must be limited by preventing unnecessary job loss. In the formal sector, this could be done by strengthening job-security policies so as to avoid the dismissal of workers with TB and MDR-TB. In the informal sector, resolving the problem of income loss would be more of a challenge. Whatever the case, it is important to design a legal framework that provides additional social protection, not only to compensate patient's income loss, but also to prevent further severe TB-related socioeconomic impact by ensuring that patients are covered by national health insurance, .

Another possible way of reducing treatment costs is to shorten the TB treatment period.[15,27] The development of a new TB drug regimen with a shorter treatment period is currently being evaluated.[28] Positive evidence that this shorter period is just as cost-effective would allow a reduction in direct non-medical costs and, as a result, a reduction in the likelihood of catastrophic cost.[29] For patients with MDR-TB, a possible way of reducing transportation costs and possible income loss is to increase the number of MDR-TB drug-delivery centres.

Unfortunately, the strategies for eliminating catastrophic costs named above would require considerable resources, while most of the TB high-burden countries are low- to middle-income countries with limited resources for social-protection policies.[3] If global action to combat TB does not become more innovative and is not given more funding, such countries will be left with very little chance of attaining the target stipulated in the WHO's 2020 and 2025 milestones of zero percent of families that face catastrophic costs.

The limitations of this study fall into two main categories. First, we enrolled only TB and MDR-TB patients who had been treated in public health services, and thus not in the private sector. We did not interview patients who had dropped out of treatment, and we excluded any TB patients or suspected TB patients who had not followed standard TB diagnostic and treatment procedures. Similarly, the only MDR-TB patients we interviewed were those who had been treated in a national pulmonary referral hospital in an urban area (Jakarta). With regard to the extent of patients' needs for social protection and to the value of cash transfers, these strict inclusion criteria may have led us to underestimate the needs of TB patients and to overestimate the needs of MDR-TB

patients. MDR-TB patients treated in other MDR-TB centers or referred to PHCs after culture conversion may have lower direct non-medical costs, and may thus have lower requirements with regard to social protection.

Secondly, while these findings may apply to the island of Java, which constitutes 60% of the Indonesian population,[30] they may not apply directly to the eastern part and other remote areas of Indonesia, where travel costs may be much higher than in Java, and where income loss may be much lower. It is also uncertain whether these findings will apply to other TB high-burden countries with a low- to middle-income.

Conclusions

Indonesia's current level of social protection is not sufficient to mitigate the socioeconomic impact of TB. Financial support for income loss, transportation costs, and food-supplement costs will substantially reduce the incidence of catastrophic costs, but financial support alone will not be sufficient to achieve the target of 0% TB-affected households facing catastrophic costs. This would require innovative social-protection policies and higher levels of domestic and external funding.

Ethics approval and consent to participation

Ethical clearance for this study was provided by the Ethical Committee at the Faculty of Medicine of Universitas Indonesia–Cipto Mangunkusumo Hospital, Jakarta Indonesia (No. 416/UN2.F1/ETIK/VI/2016); and the Ethical Committee at Persahabatan Hospital, Jakarta, Indonesia (No. DL.01.03/II.3/3817/2016). Before their decision to sign the informed-consent form, patients were provided with written and oral explanations. We confirmed that all respondents had received written and oral explanations of the study, and that they had signed an informed consent form before the interview.

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Chapter 7

Discussion

This thesis is intended to provide three evidence bases related to TB in the context of UHC in Indonesia: the household-level economic impact of TB, the relationship between catastrophic costs and TB treatment outcomes, and the social-protection improvements that are required to further reduce TB-related catastrophic costs. Below, I first describe the economic impact of TB and the contribution made by private healthcare providers to the economic impact of TB. Next, I present evidence on the relationship between catastrophic costs, treatment adherence and treatment outcomes. Finally, I explore the potential effect of further social-protection measures (i.e. those beyond UHC) on the incidence of catastrophic costs.

To answer the research questions outlined in my Introduction, this chapter provides a detailed discussion of the main findings. It also addresses several methodological issues and the implications for further research and policy making.

Main findings

The economic impact of TB

Research Question 1: What is the economic impact of TB faced by TB-affected households?

Despite the implementation of UHC in Indonesia, we found that TB-affected households still incurred high costs to access TB-related services. These costs were often catastrophic. We also found that, after diagnosis, many TB patients quit their jobs, had to deal with high costs by borrowing money or selling property, and found that access to TB-related services causes them moderate to severe financial problems.

The incidence of catastrophic costs is an important indicator of the economic impact of TB. It is one of the targets addressed in the WHO's End TB Strategy: to reduce to zero percent the incidence of catastrophic costs faced by TB-affected households. In Chapter 3, we show that the incidence of catastrophic costs in Indonesia remains high: 36% for TB-affected households and 83% for MDR-TB-affected households.

The households most affected by catastrophic costs were poor ones – even though, in absolute terms, they spent less than non-poor households to access TB-related services. On the basis of a threshold of 20% of annual household income, the incidence of catastrophic costs faced by poor TB-affected households (43%) was significantly higher

than that faced by non-poor TB-affected households (25%). As well as this higher incidence of catastrophic costs (H), poor households also had to deal with a mean gap (G) of 13%. This gap, which represents the average amount whereby total costs as a proportion of household income exceed the threshold of catastrophic costs, was much higher than the mean gap of 5% faced by non-poor households. In terms of the mean positive gap (MPG), which is calculated by G/H in order quantify the excessive cost incurred by households experiencing catastrophic costs, poor households also suffered much more than non-poor households: 30% *vs* 18%. Among MDR-TB-affected households, poor households also suffered more than non-poor households. Although the incidences of catastrophic costs were the same in poor and non-poor households (83% when we used a threshold of 20% of annual household income), poor households faced a deeper impact; this is indicated by both the G (138% *vs* 45%) and the MPG (167% *vs* 55%).

As shown Chapters 3 and 4, patients incurred high costs even during the pre-diagnostic phase, i.e. the period between starting to seek care to relieve TB-related signs and symptoms and finally obtaining a diagnosis of TB. It is important to note that it was in this phase that the effect of Indonesia's national health insurance program on TB-related costs for households was expected to become apparent. This is because, if patients received TB treatment at facilities linked to the National Tuberculosis Program (NTP), the direct medical costs incurred during the treatment phase would already have been covered. The introduction of Indonesia's national health insurance program in 2014 had also ensured that, provided diagnosis was sought at healthcare providers linked with BPJS-K – the national health insurance agency (*Badan Penyelenggara Jaminan Sosial Kesehatan*) – direct medical costs incurred during the pre-diagnostic phase would also be covered.

However, despite the national health insurance program, the reality is that patients still faced high direct costs during the pre-diagnostic phase – not only direct medical costs such as consultation fees and diagnostic tests, but also direct non-medical costs, such as transportation and food costs. The direct medical costs incurred during the pre-diagnostic phase resulted mainly from medical consultations with private health providers. These providers are discussed in detail below, under the sub-heading 'Private healthcare providers and the economic impacts of TB.'

Chapters 3 and 5 nonetheless demonstrate that most of the costs of accessing TB-related services were indeed faced during the treatment phase, amounting to 88% of the median total costs for TB-affected households, and 98% for MDR-TB-affected households. Although the NTP covers the direct medical costs, including free TB and MDR-TB drugs, these were not the only direct medical costs patients incurred: there were also others, such as administrative costs for patients with TB, and hospitalization for those with MDR-TB. Nevertheless, the contribution of these two items to the total costs was very small (<1% of the median total costs). During the treatment phase, direct costs consisted mostly of non-medical costs: those for transportation (5% of the median total costs in TB-affected households and 14% in MDR-TB-affected households) and for food supplements (10% and 6% respectively).

After being diagnosed with TB, the proportion of patients who lost their jobs was high: 32% of those who had had an income-earning job before the diagnosis of TB, and 69% of those with MDR-TB. These people quit their jobs for various reasons, including stigmatization in the workplace,[1] frequent visits to healthcare services,[2] and worse health.[3, 4] The impact of job loss is clear: once patients lose their job, they also lose much of their income, thereby reducing the financial capacity of their households. The average income loss to those who lost their job amounted to 80% of total costs. Even though some patients maintained their jobs during the treatment phase, healthcare visits often caused their incomes to fall, particularly in the case of those working in the informal sector. Indeed, our data show that income loss was high, even among patients who kept their jobs: the income of TB patients who had maintained their job, their income reduced by 24% (95% CI 18-30%) compared to their previous income. In the case of MDR-TB patients, this was 24% (95% CI 8-21%). As a result, household incomes fell by 15% (95% CI 8-22%) in TB-affected households and 20% (95% CI 7-33%) in MDR-TB affected households.

For many patients, the perceived economic impact of TB was severe. In Chapter 6, we found in the context of UHC that TB and MDR-TB patients perceived a need for financial support to cover direct non-medical costs (transportation costs and food supplements costs) and indirect costs (income loss). The need for support to recover income loss was higher than for support to cover other costs. This highlights the critical nature of the impact of TB on income and job loss – a problem that should be addressed properly in the global and national frameworks for combating TB.

The effect of Indonesia's national health insurance program on catastrophic costs for TB and MDR TB patients is limited because of two reasons. First, most medical costs incurred for TB treatment in PHCs were already covered by the NTP, while the national health insurance covered medical costs incurred during the pre-diagnostic phase. In the pre-diagnostic phase, nonetheless the effect of national health insurance is indeed limited according to TB-related costs incurred between patients who were beneficiaries and patients who were non-beneficiaries of the national health insurance program. While some 61% of TB patients were beneficiaries, statistically, the direct medical costs they incurred in the pre-diagnostic phase were not significantly lower than those incurred by non-beneficiaries. This indicates that, despite their health-insurance coverage, many patients sought care for diagnosis at private healthcare facilities that were not linked to the NTP and the BPJS-K. Neither did the incidence of catastrophic costs between the insurance beneficiaries and the non-beneficiaries differ significantly. Second, while the national health insurance covers direct medical costs, the largest part of the total costs incurred by TB-affected household consisted of indirect costs.

Our findings suggest that the economic impact of TB remains high. While this is due partly to the role of private healthcare providers in the pre-diagnostic phase, the most important factor is income loss in the treatment phase. In the context of UHC, Indonesia's national health insurance program is similar to the universal health insurance programs elsewhere that cover most direct medical costs. But while it is essential to these costs, they are only part of the financial burden, and covering them is not enough to mitigate the impact. A much higher economic burden is often imposed by direct non-medical costs and the indirect costs caused by job and income loss.

Private healthcare providers and the economic impacts of TB

Research Question 2: What is the contribution of private healthcare providers to this economic impact of TB?

During the pre-diagnostic phase we found that private healthcare providers had contributed significantly to the economic impact of TB. Despite the national health insurance, suspected TB patients often sought care first either at private clinics (33%) or at private hospitals (7%). The preference for these private institutes as a first point of care was significantly more common in the rural district than in the urban district, and the costs incurred at them during this phase were significantly higher than those incurred

by patients who had first visited a PHC. These high costs were due to higher direct medical costs (e.g., diagnostic tests) and direct non-medical costs (e.g., transportation costs).

The higher preference for first seeking care from a private provider (rather than at a public provider) in the rural district than in the urban may have been due to the limited number of PHCs in the rural and their limited opening hours. If so, patients may have felt encouraged to visit private healthcare providers – whether clinics, solo practices, or hospitals – that were closer to their homes or were open in the afternoon or evening. In principle, such a preference would save time and money on transportation, and avoid potential income loss. But many patients in the urban district (27%) had also sought care first from a private provider, even though their choice of public health providers was much greater. Various factors may have affected this preference: unawareness of the free TB service provided by the PHCs, the inconvenient consultation hours and long waiting times at PHCs, or perceptions that the quality of care provided there was low.[5]

In Chapter 4, we also reported that the preference for first seeking care from a private clinic had led to a significantly higher average number of healthcare visits (3.06, 95% CI 2.83-3.30) than first seeking care from a PHC (2.18, 95% CI 1.96-2.41). This higher average number may have resulted from additional visits needed for referral for diagnostic tests. As many private providers have no laboratory facilities, they referred suspected TB patients for diagnostic tests to a PHC, hospital, or referral laboratory.[6] The higher number of visits may also have been due to the low quality of TB diagnostic care given by a private healthcare provider, or to its poor adherence to the TB care guidelines.[7]

Although it is assumed that the UHC provided through the national health insurance program would reduce costs in the pre-diagnostic phase, we found no difference between insurance beneficiaries and non-beneficiaries with regard to the following: their choice of public or private providers as the first point of care, the number of healthcare visits they had made, and the costs they had incurred during the pre-diagnostic phase. Instead, we did find that average total pre-diagnostic costs were higher for patients whose first point of contact had been a private clinic (USD 32; 95% CI USD 23-41) or a private hospital (USD 37; 95% CI USD 22-52) than whose first point of contact had been a PHC (USD 14; 95% CI USD 10-17).

In principle there are four main explanations for the higher TB-related costs incurred by those who visited private providers. First, as many private providers are not linked to the BPJS-K, patients still pay for medical costs. Our additional analysis did indeed show that the medical costs incurred at private clinics (USD 21; 95% CI USD 15-28) and private hospitals (USD 32; 95% CI USD 17-48) were significantly higher than those at PHCs (USD 5; 95% CI USD 3-7), while travel costs between private providers and PHCs did not differ significantly (see **Annex E**).

Second, patients who first sought care from private hospitals breached the referral system. It is also the case that the national health insurance program does not allow patients to visit a private hospital unless they have been referred by a provider at primary-care level; the costs are otherwise paid out-of-pocket, which is very expensive. Nonetheless, in Chapter 4, we found that 7% of TB patients had first sought care from a private hospital rather than from a primary healthcare facility.

The third possible explanation for the higher TB-related costs incurred by those who visited private providers is that while private providers may be linked to the BPJS-K, their poor quality of TB service leads patients to misdiagnosis or delays in undergoing diagnostic TB tests, both of which can result in higher direct and indirect costs.

The fourth possible explanation lies in the fragmented connection between the national health insurance program and the system under the NTP. Despite their linkage to the BPJS-K, private providers may be unaware of the current guidelines for TB care management[5] and the free TB diagnostic tests available from BPJS-K-linked or NTP-linked facilities.[8] Such unawareness might have led to the higher direct medical costs during pre-diagnostic phase. On the other hand, coordination between BPJS-K and private providers is often poor, as is the exchange of information between them. In many cases, private providers are also afraid that if they refer a patient to another facility, the patient will be transferred completely, thereby losing them the patient and the income from the capitation payment – payment system based on the number of members registered in a primary-level healthcare provider.[9] As a result, private providers prefer to keep their patients, and not to refer them to other healthcare facilities. Potentially this leads to misdiagnosis, delay to diagnosis, and eventually higher costs incurred by patients.

In summary, as a high proportion of suspected TB patients first seek care from private healthcare providers, the costs they incur in the pre-diagnostic phase are higher than

they would have been at a PHC. This is due largely to the higher medical costs (e.g., consultation fee, drug costs, and diagnostic tests costs). However, the costs incurred in this phase make only a limited contribution to the total TB-related costs, the greater part of which is incurred during the treatment phase, and consists mainly of indirect costs due to income loss. These findings makes it imperative to develop a comprehensive strategy for overcoming the economic impact of TB, which could be mitigated by taking action on three fronts: bridging the gap between the BPJS-K and the NTP in the TB care-delivery system, improving the quality of the TB care given by private providers, and, once a patient has been diagnosed, following a suitable strategy to ensure that he or she does not suffer income loss.

Catastrophic costs, treatment outcome and treatment adherence

Research Question 3: Do catastrophic costs affect patients' TB treatment adherence and treatment outcome?

Our study shows that TB-related catastrophic costs have a negative impact on treatment outcome. The odds of an unsuccessful treatment outcome were two to three times higher among patients who had experienced catastrophic costs than among those who had not. While our findings were statistically significant at a threshold for catastrophic costs of 30%, there was an indication that this may also be the case at thresholds between 10% and 25%. Due to the possibility of reverse causation, the association between catastrophic costs and TB treatment adherence is more complicated. Catastrophic costs, on one side, may cause poor adherence. On the other side, poor adherence can also lead to prolonged treatment that results in a higher proportion of households to face catastrophic costs. After adjustment for such reverse causation, we found at thresholds of 10% and 15% that catastrophic costs had negatively affected treatment adherence. The odds of poor treatment adherence were approximately twice as high for patients who had experienced catastrophic costs than for those who had not.

In Chapter 5, we found at a threshold of 30% that catastrophic costs had had a statistically significantly negative impact on treatment outcome; we also found an indication that this may also be the case at thresholds between 10% and 25%. At a threshold of 30% of annual household, the odds of unsuccessful treatment outcome were 3.86 times higher (95% CI 1.11-13.38, P=0.03) in patients who had experienced catastrophic costs than in those who had not. On the basis of this adjusted odds ratio,

the population-attributable fraction (PAF) is 38.6%, meaning that the unsuccessful outcome experienced by 38.6% of patients cases whose treatment outcome were unsuccessful could be attributed to catastrophic costs.

The association between catastrophic costs and TB treatment adherence is more complicated than the association between catastrophic costs and treatment outcomes. This is due mainly to potential reverse causation. We found that higher costs, including catastrophic costs, were associated with poor treatment adherence. At a threshold of 15% of annual household income, the odds of poor treatment adherence were 2.35 (95% CI 1.08-5.14, *P*=0.03) times higher in patients who had experienced catastrophic costs than in those who had not. However, it is possible that, due to financial constraints, a patient does not visit the PHC regularly, but still remains in treatment. Despite poor adherence, a patient may remain in TB treatment, either out of a feeling of obligation towards medical staff to finish TB treatment, or because he or she wishes to avoid any future recurrence. Such behaviour may extend TB treatment in a way that eventually leads not only to higher costs for transportation and food, but also to higher loss of income loss. Eventually, such a sequence would lead to a higher incidence of catastrophic costs. After adjusting for such reverse causation, we found that, at the 10% threshold, the odds of poor adherence were 2.11 times higher (95% CI 0.97-4.59, *P*=0.059) in patients who had experienced catastrophic costs than in those who had not. Findings were similar at the 15% threshold (aOR 2.06, 95% CI 0.95-4.46, *P*=0.07). However, due to the size of our study and lack of statistical power, although there is indication of a similar effect at the thresholds of 20-30%, we need to be cautious with drawing firm conclusions with respect to these levels.

Our findings provide evidence of the effect of catastrophic costs on treatment outcomes and treatment adherence in a middle-income, TB high-burden country. Until now, the only study which assessed the association between catastrophic costs and poor treatment outcome was the Peruvian study (2014) which suggested a threshold of 20%.[10] Apart the evidence provided by that Peruvian study, there is very little evidence on the effect of catastrophic costs on treatment outcomes. Although the WHO now recommends that sensitivity analyses use several thresholds to measure the incidence of catastrophic costs,[11] it is also essential to define which indicators are important in the context of a TB-control program at national and regional levels. Our findings suggest that if poor treatment adherence is an important issue, it would be better to consider defining catastrophic costs on the basis of a lower threshold, i.e., 15% of annual

household income. If TB treatment outcome is an important issue, a higher threshold – 30% of annual household income – might be considered.

TB-related catastrophic costs negatively affect TB treatment outcomes and adherence. The new evidence provided by our findings can inform a review of the threshold at which these costs should be measured in future global policy. However, the effect of catastrophic costs on treatment outcomes and adherence – and at which threshold – should be carefully assessed according to the definition of variable measurement, the national burden of TB, and the targets of the TB control program. These findings highlight the need for TB control interventions to properly address the socioeconomic aspects of the disease.

Potential effect of further social protection beyond UHC

Research Question 4: What is the potential effect on the incidence of catastrophic costs of further social-protection measures beyond UHC?

Indonesia's current national health insurance program covers the direct medical costs incurred at healthcare providers linked to the BPJS-K, while the NTP provides free TB treatment with healthcare providers linked to the NTP. Nonetheless, these two programs are not enough to mitigate the economic impact of TB, and the incidence of catastrophic costs remains high. Patients therefore need additional financial support to cover three prominent cost items: income loss, transportation costs, and food supplement costs. The simulation study we present in Chapter 6 shows that the provision of support for a combination of these three items would substantially reduce the incidence of catastrophic costs. But as financial support alone will not be enough to eliminate this incidence to zero percent, other social-protection measures – such as job security policy and social community support – are also necessary.

In short, TB-affected households need additional financial protection to mitigate the socioeconomic impact of TB. Our study shows that 48% of TB patients and 78% of MDR-TB patients perceive TB to cause moderate to severe financial problems in their households. The proportion of patients who face income loss is also high (61% in TB-affected households and 86% in MDR-TB-affected households). As 24% of TB patients and 34% of MDR-TB patients indicate, income loss is at the top of the list of items that

most need to be covered. Next on the list are financial protection to cover transportation costs (19% and 42%) and food supplements (15% and 8%).

As our simulation studies show, providing cash transfers beyond UHC would substantially reduce the incidence of catastrophic costs. Cash transfers for a combination of three cost items – income loss, transportation, and food supplements – would do most to reduce the incidence of catastrophic costs: by 25 percentage points in TB-affected households (from 36% to 11%), and by 60 percentage points in MDR-TB-affected households (from 83% to 23%). However, these alternative scenarios did not consider patients or households' behavioural effects in response to the cash transfer. In the case of cash transfer, patients or houesholds may consume it for other purposes that are not related to TB treatment, such as for covering transportation costs to healthcare facility. Therefore, we need to be cautious with drawing firm conclusions with regards to the effect of the cash transfers.

Cash transfers to TB-affected households would have a greater effect in poor households than in non-poor households: in the baseline scenario without cash transfers, it is in poor households that the incidence of catastrophic costs is significantly higher. If both groups were provided with a cash transfer consisting of the same amount for everyone, the gap between poor and non-poor households would disappear. On the other hand, in the baseline scenario without cash transfer, the incidence of catastrophic costs among poor and non-poor MDR-TB-affected households is equally high. In most simulated scenarios, the incidence of catastrophic costs would fall, but would still remain equally high in both.

Implementing cash transfer for TB- and MDR-TB-affected households beyond UHC nevertheless requires careful assessment. First, it is difficult to determine the value of a cash transfer that would fit all patients, as the value of the cash transfers required covers a very wide range.

Second, cash transfers would demand an additional budget, whose affordability and sustainability should be considered carefully. Our simulations suggest that providing cash transfers would lead to a substantial increase in government spending on the TB and MDR-TB programs. With regard to TB-affected households, public spending on the TB program would increase by between 46% (to provide cash transfers for transportation) and 148% (cash transfers for a combination of income loss, transportation, and food supplements). With regard to MDR-TB-affected households,

the expected increase in public spending would be less: between 8% (cash transfers for transportation) and 20% (cash transfers for a combination of income loss, transportation, and food supplements). This is because MDR-TB already requires high costs for treatment.

The third matter to assess is this: to avoid the risk of stigmatization and moral hazard, the provision of cash transfers would require a systematic targeting and delivery system.[12]

As well as the national health insurance program, Indonesia has another social-protection program, the Hope Family Program (*Program Keluarga Harapan*, PKH). Previously known as the 'cash-transfer program' (*Bantuan Langsung Tunai*),[13] this targets poor households as beneficiaries of cash transfers, irrespective of whether a household member suffers from TB. Since 2019, the cash transfer has consisted of several components: a fixed cash transfer; a health-related cash transfer (if a household has one or more pregnant women and/or one or more child under five years of age); an education-related cash transfer (if a household has one or more school-aged child); a socially-related cash transfer (if a household has one or more person aged over 60; or one or more person with a disability). According to its components, the amount of cash transferred ranges between USD 67 to USD 778 per year. The transfer is made every three months, and is conditional on the household beneficiary fulfilling certain criteria, such as a minimum of four pregnancy visits for a pregnant woman and a minimum attendance of $\geq$85% of the total annual number of school days for school-aged children.[14]

In the context of TB, the PKH is a TB-sensitive initiative that has the potential to improve TB prevention, access to TB-related services, or TB treatment outcome, as poor people have a higher risk of TB and are vulnerable to deeper impoverishment as a result of it.[12] However, although the PKH is conditional, the indicator focuses much more on mother-and-child health, does not includes a TB-related indicator in the health component, and does not specifically includes access to healthcare services. To date, there has been no evidence of its effect on improving the TB control program or reducing the economic impact of TB.

Despite the UHC, additional financial support is needed for TB-affected households. Potentially, financial support in the form of cash transfers to these households can substantially reduce the incidence of catastrophic costs. Support that was specific for

TB-affected households would have a greater impact on reducing the incidence of TB-related catastrophic costs than support that was provided to a broad, non-TB-specific group, such as the support to poor households provided under the PKH. The combination of TB-specific and TB-sensitive initiatives would have a greater effect of financial support to reduce the incidence of catastrophic costs. Nevertheless, developing a cash transfer system for TB patients would be a complex process, as the amount of cash transfer that was affordable and sustainable would have to be formulated. Since cash transfers based on our simulated scenarios would require a 46-148% increase on the current TB program budget and a 8-20% increase on the current MDR-TB program budget, a strong commitment from government is imperative. To improve the effect of financial support, other innovative social-protection policies would also be required, such as strengthening policies on job security in order to avoid income loss. Neither should an income-protection system be also restricted only to TB-affected households. Instead, it should include other chronic illnesses that are in danger of leading to income loss after diagnosis.

Methodological issues

Generalizability is one of the methodological issues in our studies. While these studies captured the incidence of catastrophic costs, their association with treatment outcome and adherence, and the effect of financial support in reducing the incidence of catastrophic costs in urban, suburban, and rural districts, the districts in question were all on the island of Java. While this is the most populous island in Indonesia, and is home to 60% of Indonesian population, Indonesia covers a very wide geographical area, with many islands and remote areas. For this reason, our findings are not necessarily generalizable to parts of Indonesia whose sociodemographic and geographical characteristics and whose levels of health-service readiness differ.

It is clear that different sociodemographic and geographical characteristics may lead to different cost levels. In islands and remote areas, transportation costs are much higher than in Java, as many patients travel by boat, ferry, or taxi-bike, all of which are more expensive than more usual forms of public transport.[15] Similarly, the proportions of patients who work in the informal sector may be higher on other islands and in remote areas. While we assume that incomes will be lower than in Java, income losses may –

arguably – also be lower. Nonetheless, as patients in other parts of Indonesia incur higher transportation costs[15] but lower income losses[16] than the patients in our study, the incidence of catastrophic costs may differ only slightly from the incidence we found in our study. While income loss contributed most to catastrophic costs, we would not expect the need for additional socioeconomic support in other parts of Indonesia to differ greatly from that in our study. Meanwhile, the value of financial support that needed to be covered might be slightly lower.

With regard to other islands and other areas, it is equally clear that different levels of health-service readiness and access to healthcare services may also affect TB treatment outcomes and treatment adherence, and the relationship of both with catastrophic costs. If the number of healthcare facilities is limited and the quality of TB care is poor, this may lead to poor treatment adherence and to outcomes that prolong treatment, and thus to higher costs and greater loss of income. In such areas, the associations between catastrophic costs, treatment outcome and treatment adherence are therefore likely to be stronger than those we found in our study.

The generalizability of our findings was also limited by our inclusion criteria, which were restricted to TB patients who had undergone TB treatment in a PHC. In other words, as we did not consider TB patients treated by private providers, we did not consider the costs they incurred, the socioeconomic impact of TB, their treatment adherence, or their treatment outcomes. However, as we discussed before, the high costs incurred at private providers that were not linked to the NTP and the BPJS-K may also have increased not only the risk of poor adherence or loss to follow up, but also have led to a high number of cases with unsuccessful treatment. Private providers that are not linked to the NTP have no obligation to notify new TB cases, to follow up treatment, or to report treatment outcomes. They are also assumed to provide low quality of TB care.[7] In this context, the relationship between catastrophic costs and treatment adherence and treatment outcome may be more noticeable.

We should also indicate that private providers in Indonesia are concentrated in urban areas and in Java – all densely populated areas. Since patients elsewhere rely much more on PHCs than on private providers,[17] we believe that our restriction of inclusion to patients who had been treated in a PHC was reasonably representative for the 40% of the Indonesian population that does not live in Java.

With regard to their application to other countries, our findings naturally require careful appraisal. Private providers' levels of engagement in TB-control programs vary from one country to another.[18] The provision of UHC may also vary, especially with regard to population levels, service, and cost coverage, and also to the degree of linkage between national health insurance and private providers. For all these reasons, UHC in other countries may or may not mitigate the economic impact of TB to a greater extent than in Indonesia.

Recommendation for further research and policy

It is vital that the target for eliminating the incidence of TB-related catastrophic costs is achieved. Our studies provide evidence that might improve TB policy in this regard, but further investigations are required.

Recommendations for further research

In 2020, Indonesia will conduct a national survey of TB costs. The most important quality it should ensure is the generalizability of the study through a robust sampling method and a sample size that is sufficient to capture the situation throughout Indonesia.

It is also important that it captures the TB costs incurred by patients of private healthcare providers. For comparative purposes, samples of private providers should therefore include private providers that have links to the NTP only, those that have links to the BPJS-K only, those that have links to both, and those that have no affiliation to either the NTP or the BPJS-K. The 2020 cost survey can use the adapted questionnaire provided in this thesis.

While the incidence of catastrophic costs is obvious, it is essential that further research determines how social protection should ensure that future costs of this sort are avoided. This study has already highlighted the need for additional social-protection measures in terms of cost items and the value of cash transfers.

A further step towards formulating financial protection for an intervention study is to involve as many TB-related stakeholders as possible. Protection should not be limited to finances alone, but should also include social issues such as the provision of

community support[19, 20] and workplace-based interventions for avoiding unnecessary job loss.

Before a final recommendation for social-protection measures is produced, qualitative studies through interviews and focus group discussions are also necessary. These will also help harmonize social-protection measures not only for TB patients, but also for other groups.

Recommendations for further policy

As there is no single recipe for formulating a social-protection package, the context needs to be considered carefully. Eliminating catastrophic costs requires a clear understanding not just of patients' needs and the government resources required, but also of the strategies that can be combined.

First, we recommend that the TB control program is integrated into the national health system. Any strategy for this should ensure that the referral system between healthcare providers for TB diagnosis and treatment is redefined in ways that allow (1) TB drugs to be covered by the national health insurance benefit package, (2) TB-related indicators to be incorporated with the performance-based capitation payment, and (3) improvements in the quality of TB care in both public and private healthcare providers.

Second, action should be undertaken to increase patients' – and potential patients' – awareness not only of the signs and symptoms of TB, but also of the wider range of facilities they can approach. The number of public healthcare facilities, particularly in rural districts, should be increased. If the role of community health workers (CHWs) is reinforced, it may be possible to avoid (or at least reduce) the transportation costs and income loss caused by visits to healthcare facilities

Third, our findings show that the incidence of catastrophic costs would be reduced by combining the financial support. However, to formulate the support that could be provided, needs assessment will be necessary. To establish the affordability and sustainability of providing socioeconomic support, we recommend consultation with key stakeholders including the NTP, local government, public and private healthcare providers, community health workers, and patients.

Fourth, we recommend that TB control programs should incorporate a broader social-protection strategy. This should include improvement of TB awareness and education in the workplace, reinforcement of the national job security policy (to avoid unnecessary job loss); and enhancement of the sickness fund policy in order to cover situations in which TB patients need to take temporary leave. Finally, as a high proportion of workers in informal sectors are still not covered by Indonesian national health insurance,[21] the financial burden imposed upon them by medical costs must be reduced by bringing these workers into the national health insurance program.

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Summary

Summary

Tuberculosis (TB) is an infectious disease with a very long history. Although there have been strategies including drug development, effective treatment and socioeconomic development to eliminate TB, still an estimated 10 million TB incident cases and 1.33 million TB patients died in 2017. The incidence of TB also remains high in Indonesia – a country with the third highest incidence in the worldwide.

Meanwhile, accessing TB-related services is often costly, and can be catastrophic for TB-affected households. In addition to eliminate the incidence of TB, the WHO End TB Strategy also sets a target to reduce to zero percent the percentage of TB-affected households that faced catastrophic costs – defined as the total costs incurred by TB-affected households that exceed a specific threshold of the household's annual income.

In 2014, Indonesia started a national health insurance program (*Jaminan Kesehatan Nasional*, JKN) to achieve universal health coverage (UHC). An extensive network of public and private providers has been improving. As beneficiaries of the national health insurance can access free essential health services, this program is assumed to reduce TB-related direct medical costs. Even though patients receive free TB drugs and medical consultations, they still incur high costs for direct non-medical costs, such as transportation and food during their visits to the healthcare facility, indirect costs that are resulted from income or job loss. Such economic consequences can be still catastrophic, particularly for poor households. In Indonesia, no evidence has yet been produced on measurements of the incidence of catastrophic costs due to TB, neither is there currently any evidence on the extent to which households still face catastrophic costs since UHC was implemented through the JKN program.

In the context of UHC in Indonesia, this thesis aims to provide an evidence-base on the household-level economic impact of TB, the relationship between catastrophic costs and TB treatment outcomes, and the social-protection improvements required to further reduce TB-related catastrophic costs.

We find that, despite the implementation of UHC in Indonesia, TB-affected households still incur high costs to access TB-related services. The incidence of catastrophic costs is high: 36% for TB-affected households and 83% for MDR-TB-affected households. Also, TB patients often quit their job after diagnosis, must cope with the high cost by borrowing money and selling property, and perceive that accessing TB-related services

causes moderate to severe financial problems. In the context of UHC, the national health insurance program in Indonesia is comparable to universal health insurance programs in many countries that cover most direct medical costs. Although covering direct medical costs is essential, it is only a part of the financial burden; and it is not enough to mitigate the financial impact of TB. Direct non-medical costs and indirect costs due to job and income loss often constitute a much higher economic burden than the direct medical costs.

There is still a high proportion of suspected TB patients seeking care first with private healthcare providers. A first contact with a private provider contributes to higher costs during the pre-diagnostic phase compared to a first contact at a PHC. The higher costs in this phase largely result from the higher medical costs (e.g., consultation fee, drug costs, and diagnostic tests costs). However, the costs incurred in the pre-diagnostic phase have limited contribution to the total costs due to TB because the largest part of the total costs are incurred during the treatment phase – and mostly consist of indirect costs due to income loss. To mitigate the economic impact of TB, bridging the gap between the national health insurance agency (*Badan penyelenggaran Jaminan Sosial Kesehatan*, BPJS-K) and the National Tuberculosis Program (NTP) in TB care delivery system and improving the quality of TB care in private providers should be combined with a strategy to avoid income loss once a patient is diagnosed with TB.

Mitigating TB-related costs is important since catastrophic costs due to TB – according to our findings – negatively affect TB treatment outcomes and adherence. Our findings provide new evidence that can inform a review of the threshold at which catastrophic costs should be measured in the future global policy. However, the effect of catastrophic costs – and at which threshold – on treatment outcomes and adherence should be carefully assessed according to how an NTP defines treatment outcome and adherence in its national context, and targets of the TB control program.

Additional financial support beyond UHC is needed for TB-affected households. Potentially, financial support in the form of cash transfers to these households can substantially reduce the incidence of catastrophic costs. The financial support that combine TB-specific and TB-sensitive approach would provide a greater effect on reducing the incidence of catastrophic costs. Nevertheless, developing a cash transfer system for TB patients would be a complex process, as the amount of cash transfer that is affordable and sustainable would have to be formulated. To improve the effect of

financial support, other innovative social-protection policies are required, such as strengthening policies on job security in order to avoid income loss. Neither should an income-protection system be restricted to TB-affected households. Instead, it should include other chronic illnesses that may lead to income loss after diagnosis.

As there is no single recipe for formulating a social-protection package, the context needs to be considered carefully. Eliminating catastrophic costs requires a clear understanding not just of patients' needs and the government resources required, but also of the strategies that can be combined including (1) the integration between the TB control program and the national health system, (2) the improvement of awareness of the signs and symptoms of TB, as well as of the wider range of facilities patients can approach, (3) the combination of the financial support, and (4) the incorporation of the TB control program into a broader social-protection strategy.

Samenvatting

Tuberculose (tbc) is een besmettelijke ziekte met een zeer lange geschiedenis. Hoewel er gecombineerde strategieën zijn geweest, waaronder de ontwikkeling van geneesmiddelen, effectieve behandeling en sociaaleconomische ontwikkeling om tbc te elimineren, waren er in 2017 nog steeds naar schatting 10 miljoen gevallen van tbc en stierven 1,33 miljoen tbc-patiënten. De incidentie van tbc blijft ook hoog in Indonesië - een land met de derde hoogste incidentie in de wereld.

Ondertussen is toegang tot tbc-gerelateerde diensten vaak duur en kan het financieel catastrofaal zijn voor huishoudens met tbc. Naast het elimineren van de incidentie van tbc, heeft de WHO End TB-strategie ook de doelstelling geformuleerd om het percentage tbc-getroffen huishoudens met catastrofale kosten tot nul procent terug te brengen. Catastrofale kosten worden hierbij gedefinieerd als de totale kosten gemaakt door tbc-getroffen huishoudens die, als proportie van het jaarinkomen van huishoudens, een specifieke drempel overschrijden.

In 2014 startte Indonesië een nationaal ziekteverzekeringsprogramma (Jaminan Kesehatan Nasional, JKN) om een nationale dekking van ziektekostenverzekering (UHC) te bereiken. Een uitgebreid netwerk van publieke en private gezondheidszorgaanbieders is verbeterd. Omdat begunstigden van de nationale ziektekostenverzekering toegang hebben tot gratis essentiële gezondheidszorg, wordt ervan uitgegaan dat dit programma de tbc-gerelateerde directe medische kosten vermindert. Hoewel patiënten gratis tbc-medicijnen en medische consulten ontvangen, maken ze nog steeds hoge directe niet-medische kosten, zoals voor vervoer en voedsel tijdens hun bezoeken aan de kliniek, en indirecte kosten die het gevolg zijn van inkomensverlies of zelfs het verlies van hun baan. Dergelijke economische gevolgen kunnen nog steeds catastrofaal zijn, vooral voor arme huishoudens. In Indonesië is er nog geen wetenschappelijke bewijs over de incidentie van catastrofale kosten als gevolg van tbc. Er is momenteel ook geen bewijs voor de mate waarin huishoudens nog steeds geconfronteerd worden met catastrofale kosten sinds UHC werd geïmplementeerd via het JKN-programma.

In de context van UHC in Indonesië beoogt dit proefschrift wetenschappelijke evidentie te leveren met betrekking tot de economische impact van tbc op huishoudensniveau, de relatie tussen catastrofale kosten en de effecten van tbc-behandeling, en de

verbeteringen in het sociale zekerheidsstelsel die nodig zijn om tbc-gerelateerde catastrofen verder te verminderen..

We constateren dat, ondanks de implementatie van UHC in Indonesië, tbc-getroffen huishoudens nog steeds hoge kosten maken om toegang te krijgen tot tbc-gerelateerde diensten. De incidentie van catastrofale kosten is hoog: 36% voor huishoudens met tbc en 83% voor huishoudens met MDR-tbc (multiresistente tbc). Ook moesten tbc-patiënten na diagnose vaak hun baan opzeggen en moesten ze manieren vinden om om te gaan met de hoge kosten door geld te lenen en onroerend goed te verkopen. Tbc-patiënten waren van mening dat het gebruik van tbc-gerelateerde diensten matige tot ernstige financiële problemen veroorzaakten. In de context van UHC is het nationale ziekteverzekeringsprogramma in Indonesië vergelijkbaar met universele ziektekosten-verzekeringsprogramma's in veel andere landen waar de meeste directe medische kosten worden gedekt. Hoewel het dekken van directe medische kosten essentieel is, is het slechts een deel van de financiële last; en het is niet voldoende om de impact te verzachten. Directe niet-medische kosten en indirecte kosten als gevolg van verlies van baan en inkomsten vormen vaak een veel hogere financiële last dan de directe medische kosten.

Nog steeds zoekt een groot deel van vermoedelijke tbc-patiënten eerst hulp bij particuliere zorgverleners. Een eerste contact met een particuliere zorgverlener draagt bij aan hogere kosten tijdens de pre-diagnostische fase in vergelijking met een eerste contact bij een PHC. De hogere kosten in deze fase zijn grotendeels het gevolg van de hogere medische kosten (bijvoorbeeld consultatiekosten, medicijnkosten en diagnostische testkosten). De kosten in de pre-diagnostische fase hebben echter een beperkte bijdrage aan de totale kosten als gevolg van tbc omdat het grootste deel van de totale kosten wordt gemaakt tijdens de behandelingsfase - en meestal bestaan uit indirecte kosten als gevolg van inkomensverlies. Om de financiële gevolgen van tbc te verzachten, moet de kloof tussen de nationale zorgverzekeraar (*Badan Penyelenggaran Jaminan Sosial Kesehatan*, BPJS-K) en het nationale tbc-programma (NTP) in het zorgsysteem voor tbc worden gedicht en de kwaliteit van de tbc-zorg door particuliere zorgverleners worden verbeterd en gecombineerd met een strategie om inkomensverlies te voorkomen zodra een patiënt wordt gediagnosticeerd met tbc.

Het verminderen van tbc-gerelateerde kosten is belangrijk omdat catastrofale kosten als gevolg van tbc, volgens onze bevindingen, een negatieve invloed hebben op de

behandelingsresultaten en therapietrouw bij tbc. Onze bevindingen kunnen een evaluatie van de drempelwaarde voor catastrofale kosten in toekomstig beleid informeren. Het effect van catastrofale kosten - en bij welke drempelwaarde - op de behandelresultaten en therapietrouw moet echter zorgvuldig worden beoordeeld aan de hand van hoe een NTP de behandeluitkomst en therapietrouw definieert in de nationale context en in de doelstellingen van het tbc-bestrijdingsprogramma.

Aanvullende financiële ondersteuning naast de nationale ziektekostenverzekering is nodig voor huishoudens die getroffen zijn door tbc. Financiële steun in de vorm van contant geldoverdrachten aan deze huishoudens kan de incidentie van catastrofale kosten aanzienlijk verminderen. De financiële steun die een tbc-specifieke en tbc-gevoelige aanpak combineert, zou een groter effect hebben op het verminderen van de incidentie van catastrofale kosten. Desalniettemin zal het ontwikkelen van een systeem voor financiële uitkeringen aan tbc-patiënten een ingewikkeld proces zijn, aangezien de hoogte van het uit te keren bedrag zodanig moet worden vastgesteld dat het programma betaalbaar en duurzaam is. Om het effect van financiële steun te versterken, zullen ook andere innovatieve beleidsmaatregelen op het gebied van sociale zekerheid nodig zijn, zoals een versterking van het beleid om baanverlies en inkomstenverlies bij ziekte te voorkomen. Een inkomensbeschermingssysteem mag niet alleen worden beperkt tot huishoudens die door tbc zijn getroffen. In plaats daarvan zou het ook andere chronische ziekten moeten omvatten die na diagnose kunnen leiden tot inkomensverlies.

Er is geen uniform recept voor het formuleren van een pakket van sociale zekerheidsmaatregelen. De context waarin dergelijke maatregelen worden geformuleerd moet zorgvuldig worden overwogen. Het elimineren van catastrofale kosten vereist een duidelijk inzicht, niet alleen in de behoeften van patiënten en de benodigde overheidsmiddelen, maar ook van de strategieën die kunnen worden gecombineerd, waaronder (1) de integratie tussen het tbc-bestrijdingsprogramma en het nationale gezondheidssysteem, (2) de verbetering van kennis in de bevolking van de symptomen van tbc, evenals van het bredere scala aan gezondheidszorgfaciliteiten die ze kunnen benaderen, (3) de combinatie van de financiële steun en (4) de integratie van het tbc-bestrijdingsprogramma in een bredere strategie voor sociale zekerheid.

Annexes

Annex A

Changes of the tool from the Generic Tool to the Phase 1 Tool and to the definitive Phase 2 Tool

No	Question	Changes applied in	Phase 1 Study	Phase 2 Study
1	Category of facility	Choices	Generic Tool retained	Adapted to type of facilities in Indonesia: PHCs, private clinics, public hospitals, private hospitals, and others
2	Ethnicity	Question	Question added	Generic Tool retained; Question in Phase 1 Study deleted
3	Education	Question	Question added	Choices added
4	Type of TB	Choices	Generic Tool retained	Translated "smear" to "BTA"
5	Currently in intensive or continuation phase?	Choices	Choices added for MDR TB	Generic Tool retained
6	Date of first diagnostic examination	Question	Question deleted	Generic Tool retained
7	Date of starting treatment	Question	Question deleted	Generic Tool retained
8	What symptoms did you experience?	Question	Question deleted	Generic Tool retained, choice changed from "months" to "weeks"
9	Where did you seek treatment?	Question	Question deleted	Generic Tool retained, choices referring to “category of facility” adapted
10	Have you visited a traditional healer?	Question	Question deleted	Phase 1 study retained; question deleted
11	Why didn’t you go to the public health facility?	Question	Question deleted	Generic Tool retained, choice of "belief system" deleted
12	Patient income loss	Question	Question added	Phase 1 study retained; question added
13	Insurance reimbursement	Question	*Pengembalian asuransi*	*Reimbursement asuransi*
14	Guardian costs (pre-diagnostic and diagnostic)	Form	Changed to table form	Phase 1 study retained; changed to table form (four questions in four columns)
15	Cost-related DOT	Question set (6 questions)	Generic Tool retained	Question set deleted (6 questions)
16	How often do you travel to health facility to take TB drugs?	Sub-question	Generic Tool retained	Sub-questions "intensive phase" and "continuation phase" added
17	Cost related to follow-up test	Form	Generic Tool retained	Form changed to three columns to ease filling in the form
18	Income loss suffered by guardian (someone accompanying patient)	Question	Question added	Phase 1 study retained; question added
19	How much does your friend/family earn per day?	Choices	Choices changed	Phase 1 study retained; choices changed
20	Why did someone accompany you to	Question	Question deleted	Phase 1 study retained; question deleted

No	Question	Changes applied in	Phase 1 Study	Phase 2 Study
	travel to health facility to take TB drugs?			
21	How much did you pay in the hospital?	Sub-question	Generic Tool retained	Sub-question deleted
22	How much does your friend/family earn per day?	Choices	Choices changed	Phase 1 study retained; choices changed
23	Did any other family/friend visit you to while you were in hospital?	Question set (4 questions)	Question deleted	Phase 1 study retained; Questions deleted (4 questions)
24	Moving costs	Question set (2 questions)	Question set added	Question set added, and sub-questions added to allow participant to state room/house rental price "per week", "per month", or "per year"
25	Type of supplement	Sub-question	Generic Tool retained	"Drinks" changed to "milk"
26	Other illnesses	Question set (6 questions)	Question set deleted	Question set deleted (6 questions)
27	Adverse effects of TB drugs	Question set (2 questions)	Question set added	Question set added and wordings changed
28	Insurance type	Choices	Generic Tool retained	Adapted to insurance type in Indonesia: BPJS *Kesehatan* (PBI, non-PBI), *swasta*
29	How much have you received as reimbursement?	Sub-question	Sub-questions added	Phase 1 study retained; sub-questions added
30	Additional support	Question	Question added	Generic Tool retained; question in Phase 1 Study deleted
31	To what extent does TB illness affect your household financial situation?	Question	Question added	Question added and choices changed
32	Where did you earn money to pay the TB costs incurred?	Question	Question added	Generic Tool retained; question in Phase 1 Study deleted
33	What is the interest rate on the loan?	Choices	Choices changed	Phase 1 study retained; choices changed
34	What is the estimated market value of property you sold?	Choices	Choices added	Generic tool retained; the order of questions changed by substituting the next question for this one
35	How much did you earn from selling that property?	Choices	Choices added	Generic tool retained; the order of questions changed by substituting the previous question for this one
36	Did the money you earn from selling property conform to the market value of property you sold?	Question	Generic Tool retained	Question and choices inserted
37	Who is the primary income earner?	Choices	Choices changed	Phase 1 study retained; choices changed

No	Question	Changes applied in	Phase 1 Study	Phase 2 Study
38	What is the level of education of…	Question set (4 questions)	Question set deleted	Question set deleted (4 questions)
39	Are you currently formally employed?	Question	Generic Tool retained	"Currently" changed to "before being diagnosed with TB"
40	Is the (patient's) reason for not working related to TB?	Question	Question deleted	Phase 1 study retained; question deleted
41	If Yes, when was the last time you were working?	Question	Question deleted	Phase 1 study retained; question deleted
42	How were you usually paid?	Choices	Generic Tool retained	Adapted to situation in Indonesia
43	What was your estimated personal take home earning per month BEFORE the TB illness?	Question	Question deleted	Phase 1 study retained; question deleted
44	What is your estimated personal take home earning per month NOW?	Question	Question deleted	Phase 1 study retained; question deleted
45	Is the change related to TB illness?	Question	Question deleted	Phase 1 study retained; question deleted
46	If Yes (stopped working/going to school/doing housework): for how long?	Choices	Generic Tool retained	Choices deleted; question changed to open question
47	How regularly did you work before you fell ill with TB?	Question	Question deleted	Phase 1 study retained; question deleted
48	Did you have to change jobs before you came ill with TB?	Question	Question deleted	Phase 1 study retained; question deleted
49	What is your main occupation?	Question	Question deleted	Phase 1 study retained; question deleted
50	How many hours did you work on average before you came ill with TB?	Question	Question deleted	Phase 1 study retained; question deleted
51	How many hours do you work on average now?	Question	Question deleted	Phase 1 study retained; question deleted
52	Is the change related to TB illness?	Question	Question deleted	Phase 1 study retained; question deleted
53	Is someone doing the work that you used to do?	Choices	Choices changed	Phase 1 study retained; choices changed
54	Do you have children of or below school age?	Question	Question deleted	Phase 1 study retained; question deleted
55	Do all of your children attend school regularly?	Question	Question deleted	Phase 1 study retained; question deleted

No	Question	Changes applied in	Phase 1 Study	Phase 2 Study
56	If no, why not?	Question	Question deleted	Phase 1 study retained; question deleted
57	Are you financially independent?	Question	Question deleted	Phase 1 study retained; question deleted
58	Has this resulted in financial burden?	Question	Question deleted	Phase 1 study retained; question deleted
59	Has the TB illness affected your social or private life?	Question, choices	Changing wording	Phase 1 study retained; changing wording, adapting choices
60	What is your tribe/ethnic group/religion?	Question	Question deleted	Phase 1 study retained; question deleted
61	How many people regularly sleep in your household?	Question	Question deleted	Generic Tool retained, the question was moved to section before "household income and spending" section
62	How many of the household members are paid for working?	Question	Question deleted	Phase 1 study retained; question deleted
63	Besides yourself, does anyone else of your household receive treatment for TB?	Question	Question deleted	Phase 1 study retained; question deleted
64	How much food did your household consume before the TB illness?	Question	Question deleted	Phase 1 study retained; question deleted
65	How much food does your household consume now?	Question	Question deleted	Phase 1 study retained; question deleted
66	Has the amount of food consumed changed due to TB?	Question	Question deleted	Phase 1 study retained; question deleted
67	Socioeconomic indicators	Question set	Deleting 5 questions	Phase 1 study retained; 5 questions deleted
68	Do you own standard assets below...	Question set	Change questions and form	Phase 1 study retained; questions changed and formed in separated table
69	If the government could provide you with some service to ease the burden of TB on you and your household, what would you prefer to have?	Question	Generic Tool retained	Question deleted
70	How much would you have been willing to pay not to become ill with TB in the first place?	Question	Question deleted	Phase 1 study retained; question deleted
71	Have you ever heard of "social protection"?	Question	No question	Question added
72	With regard to the costs incurred for TB	Question set	No questions	Question set added, formed in two columns (the first column

No	Question	Changes applied in	Phase 1 Study	Phase 2 Study
	treatment, which types of cost created financial hardship for you, and how much financial support do you expect to receive from the government?			was type of costs, the second column was amount that is expected to receive from the government)

Annex B

Definitive version of adapted Tool to Estimate Patient Costs in Bahasa Indonesia

Perangkat untuk memperkirakan biaya yang dikeluarkan pasien

Kuesioner

Nama Pewawancara : *……*

No Registrasi Pasien di Fasilitas TB: *……..*

Tanggal wawancara (dd/mm/yy)	*Nama Provinsi*	*Nama Kabupaten / Kota*	*Nama kelurahan*	*Tempat wawancara (rumah/nama fasilitas kesehatan)*
Kategori Fasilitas Kesehatan tempat berobat	***1. Puskesmas 2. Klinik swasta 3. RSUD/ Pemerintah 4. RS Swasta 5. RS lainnya, sebutkan.....***			

Memperkenalkan diri kepada pasien:

Nama saya adalah.... Saya bekerja bersama dr. Ahmad Fuady, MSc dari Fakultas Kedokteran Universitas Indonesia. Kami melakukan studi untuk mengetahui biaya yang dikeluarkan oleh pasien karena penyakit Tuberkulosis. Oleh karena itu, kami ingin menanyakan berapa banyak biaya yang dikeluarkan untuk pelayanan kesehatan, khususnya Tuberkolusis, saat sebelum dan selama diagnosis, serta sepanjang pengobatan. Kami memohon agar Anda dapat memberikan informasi dalam tiga bulan terakhir dan sebagian besar biaya yang terkait dengan TB yang dikeluarkan sebelumnya.

Sangat penting untuk Anda pahami bahwa partisipasi Anda dalam studi ini bersifat sukarela. Kami akan sangat berterima-kasih apabila Anda bersedia ikut serta dalam studi ini, namun Anda dapat menolaknya. Jika Anda tidak bersedia ikut serta, tidak akan ada konsekuensi untuk Anda dan Anda akan tetap menerima semua pelayanan dan pengobatan di fasilitas kesehatan seperti biasa. Jika Anda membatalkan keikutsertaan Anda, Anda tidak akan kehilangan manfaat yang seharusnya Anda terima seperti pelayanan dan pengobatan yang diberikan di klinik.

Jika Anda memilih untuk ikut-serta dalam studi, Anda perlu mengetahui bahwa Anda dapat mengundurkan diri pada setiap tahap studi tanpa harus memberikan penjelasan atas pengunduran diri Anda. Semua jawaban Anda akan dirahasiakan. Pada beberapa poin kami akan menanyakan tentang penghasilan pribadi dan penghasilan rumah tangga Anda. Kami TIDAK AKAN memberikan informasi ini kepada lembaga berwenang atas pajak dan kesejahteraan, hal ini berlaku pula setelah penelitian ini berakhir.

Survey ini membutuhkan waktu sekitar 30 menit.

Apakah Anda memiliki pertanyaan? Apakah Anda akan berpartisipasi? (lingkari) **Ya / Tidak**

Tanda tangan Responden: ……..

Jika Ya : Terima kasih!

Jika Tidak : alasan tidak berpartisipasi? (lingkari) 1. Tidak cakap berbahasa 2. Kendala waktu

3. Tidak nyaman 4. Lainnya, sebutkan ……

Informasi Pasien ***(diisi oleh Pewawancara, tambahkan keterangan dari kartu pasien; diisi juga bila pasien menolak diwawancarai untuk analisis non-response)***		
Responden		1. Pasien 2. Pengawas Minum Obat (PMO)[1] / wali yang tinggal di rumah tangga yang sama dengan pasien
1. Jenis Kelamin 1. Laki-laki 2. Perempuan		Usia: …… tahun
2. Apakah pendidikan tertinggi Anda? 1. Tidak Sekolah 2. SD 3. SMP 4.SMA 5. Diploma 6. Sarjana 7. Pasca sarjana		
3. Tipe TB (lingkari)	1. Paru BTA + 2. Paru BTA - 3. Paru, tidak tahu status BTA 4. Ekstra Paru	
4. Regimen Terapi (lingkari)	1. Kat I (penderita baru) 2. Kat II (terapi kambuh atau gagal) 3. Terapi MDR	
5. Fase terapi dan lama terapi?	1. Intensif 2. Lanjutan	
6. Status HIV *(lihat di kartu pasien!)*	1. Positif 2. Negatif 3. Tidak dites 4. Tidak ada informasi	
7. Tanggal pemeriksaan dahak atau Foto toraks pertama (dd/mm/yy)		
8. Tanggal mulai pengobatan (dd/mm/yy)		
9. Berapa lama waktu yang diperlukan untuk mencapai tempat pengobatan Anda saat ini dari rumah Anda?		…… menit dengan berjalan kaki/bersepeda…… menit dengan kendaraan pribadi atau angkutan umum
Pengobatan Sebelumnya		
10. a) Pernahkah Anda mendapatkan pengobatan TB sebelumnya? *Cocokkan dengan kartu pasien;* *Jika Tidak,lanjut ke11*		1. Ya. (mm/yy pengobatan selesai)……. 2. Tidak
b) Jika YA: Apakah Anda menyelesaikan pengobatan TB Anda terdahulu?		1. Ya 2. Tidak
c) Jika TIDAK, mengapa?		1. Kekurangan biaya untuk pengobatan 2. Efek samping obat 3. Jarak tempuh ke fasilitas kesehatan 4. Lainnya (sebutkan): ……
Keterlambatan, Biaya Pradiagnosis dan Diagnosis		
11. Gejala apa yang Anda alami sehingga Anda memutuskan pergi berobat untuk penyakit Anda yang sekarang? Berapa lama Anda mengalami gejala-gejala tersebut sebelum Anda pergi mencari pengobatan? 1. Batuk YA □ TIDAK □ _____minggu 2. Keringat malam YA □ TIDAK □ _____ minggu 3. Batuk berdarah YA □ TIDAK □ _____minggu 4. Berat badan turun YA □ TIDAK □ _____ minggu 5. Lainnya (Jelaskan) YA □ TIDAK □ _____ minggu _____		
12. Ke mana saja Anda mencari pengobatan untuk mengatasi gejala-gejala tersebut? Centang semua yang sesuai		

[1] PMO: Pengawas Minum Obat yang secara khusus ditunjuk oleh pasien/penyedia layanan

1. RSUD	YA □ TIDAK □	4. Klinik Swasta	YA □ TIDAK □
2. RS Swasta	YA □ TIDAK □	5. Lainnya (Jelaskan	□ _____
3. Puskesmas	YA □ TIDAK □		

Ke mana Anda pergi pertama kali? Lingkari tempat pertama pengobatan tersebut di atas

Jika selain dari fasilitas kesehatan pemerintah yang dipilih di 12):

13. Mengapa Anda tidak pergi ke fasilitas kesehatan pemerintah, seperti Puskesmas atau RSUD, ketika Anda pertama kali ingin berobat? Lingkari yang paling sesuai.

1. Jarak terlalu jauh
2. Biaya terlalu mahal
3. Waktu tunggu terlalu lama
4. Fasilitas tidak lengkap/tersedia
5. Tidak percaya pada kualitas fasilitas kesehatan pemerintah
6. Tidak ada obat-obatan tersedia
7. lainnya (Jelaskan) : _____

14. Berapa banyak biaya yang Anda habiskan untuk setiap kunjungan sebelum Anda didiagnosis TB, termasuk kunjungan ketika Anda benar-benar menerima diagnosis Anda?

Untuk pasien MDR-TB, tanyakan hanya tentang biaya untuk diagnosis MDR-TB; untuk pasien TB lainnya, tanyakan tentang biaya untuk diagnosis TB. Untuk semua yang tidak berhubungan, tandai dengan N/A, isi satu baris per kunjungan. Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan

Kunjungan	**Penyedia Layanan**	**Total Waktu tiap kunjungan** (dalam jam, termasuk waktu perjalanan)	**Biaya Administrasi** (konsultasi, pendaftaran)	**Biaya Tes Lab** (untuk tes dahak atau lainnya kecuali Foto toraks)	**Biaya Foto toraks** (termasuk pengiriman Foto toraks ke spesialis radiologi, perjalanan dan biaya-biaya)	**Biaya Obat-obatan** (total semua jenis)	**Biaya perjalanan** (total pulang pergi, termasuk untuk ke lab, Foto toraks dll)	**Biaya Makan** (total)	**Biaya Akomodasi** (total)	**Sub-Total biaya tiap kunjungan**
Kunjungan 1										
Kunjungan 2										
Kunjungan 3										
Kunjungan 4										
Kunjungan 5										
Kunjungan 6										
Kunjungan 7										
Total										

	Kehilangan penghasil-an pasien	**Reimburse ment Asuransi** *Jika ya: jumlah dan untuk apa, jika tidak n/a*	**Diantar oleh Orang lain** *(lingkari jawaban yang tepat)*	**Biaya perjalanan untuk pengantar** (total pulang pergi)	**Biaya akomodasi untuk pengantar** (total)	**Kehilangan pendapatan yang dialami Pengantar**
Kunjungan 1			Ya / Tidak			
Kunjungan 2			Ya / Tidak			
Kunjungan 3			Ya / Tidak			
Kunjungan 4			Ya / Tidak			
Kunjungan 5			Ya / Tidak			
Kunjungan 6			Ya / Tidak			
Kunjungan 7			Ya / Tidak			
Kunjungan 8			Ya / Tidak			
TOTAL			Ya / Tidak			
Total Biaya Pra-Diagnosis & Diagnosis (jumlah subtotal) dikurangi Biaya yang diganti asuransi = ……. Rupiah						

Biaya Pengobatan (Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan

Biaya untuk pengambilan obat, baik yang langsung diminum di fasilitas tersebut, atau diminum di rumah		
Biaya yang dikeluarkan untuk pemeriksaan dan tes selama pengobatan.		
15. Apakah Anda pernah menjalani pemeriksaan/tes untuk evaluasi pengobatan sejak pengobatan dimulai? *Jika TIDAK, lanjut ke P 23.* ☐ Sputum /Tes lab Berapa kali? _____ kali Biaya Sputum (total) Rp _____ ☐ Foto toraks Berapa kali? _____ kali Biaya foto toraks (total) Rp _____ ☐ Pemeriksaan lain Berapa kali? _____ kali Biaya Pemeriksaan lain (total) Rp _____	1. Ya 2. Tidak	……. kali / bulan ……. kali / bulan
16. Seberapa sering Anda pergi ke fasilitas kesehatan untuk mengambil obat TB Anda? a. Fase intensif *b.* Fase lanjutan		
17. Berapa lama waktu yang Anda butuhkan untuk sampai ke tempat tersebut (sekali perjalanan)?	.... menit berjalan kaki ..... menit dengan kendaraan pribadi ..... menit dengan angkutan umum	
18. Berapa rata-rata total waktu yang dibutuhkan untuk sekali kunjungan, termasuk waktu perjalanan dan waktu tunggu (total waktu hingga selesai)?		….. menit
19. Dari rumah ke fasilitas kesehatan, berapa biaya transportasi yang Anda keluarkan? (pulang pergi)		…….
20. Jika Anda pergi ke fasilitas kesehatan untuk mengambil obat Anda, berapa biaya yang Anda keluarkan untuk makanan dan minuman pada hari tersebut? (di jalan, saat menunggu, dll)		Total …… ……
21. a) Apakah Anda harus membayar biaya administrasi pada saat mengambil obat TB? *Jika TIDAK, lanjut ke P 21.* b) Jika YA, berapa?		1. Ya 2.Tidak …….
22. a) Apakah ada biaya akomodasi yang harus Anda tanggung saat mengambil obat TB Anda? *Jika TIDAK, lanjut ke P 22.* b) Jika YA: berapa?		1. Ya 2. Tidak ……

Biaya yang dikeluarkan untuk pengantar saat mengambil obat dan pemeriksaan/tes evaluasi atau tindak lanjut selama pengobatan. Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan	
23. a) Apakah ada yang menemani Anda pada waktu mengambil obat dan melakukan pemeriksaan laboratorium/Foto toraks lanjutan, atau menggantikan Anda untuk mengambilkan obat Anda? *Jika tidak, lanjut ke P 244.*	1. Ya 2. Tidak
b) Jika YA, Apakah orang tersebut kehilangan pendapatannya karena pergi menemani Anda?	1. Ya 2. Tidak Jika ya, berapa jumlah total ……

c) *Jika YA* , berapa kali orang tersebut menemani atau menggantikan Anda?	..... kali

Rawat Inap Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan	
Catatan untuk pewawancara: jika pasien masih dirawat inap, tanyakan tentang kondisi terkini termasuk saat diwawancarai.	
24. Apakah Anda pernah dirawat sebelumnya (karena TB) atau selama pengobatan TB Anda? *Jika TIDAK, lanjut ke P30.*	1. Ya 2. Tidak
25. Jika YA: berapa hari Anda dirawat di rumah sakit atau Puskesmas?	…… Hari
26. Berapa biaya yang Anda keluarkan selama dirawat di rumah sakit atau Puskesmas?	Total: Rp …….
27. Apakah ada keluarga / teman yang menemani Anda selama di rumah sakit? *Jika Tidak, lanjut ke P30.*	1. Ya 2. Tidak
28. Jika YA: Berapa hari ia tinggal bersama Anda (menginap di rumah sakit)? **29.** Apakah ada biaya lain yang dikeluarkan untuk keluarga/teman Anda selama tinggal di rumah sakit? Akomodasi (rumah sakit atau lainnya): …….. Makanan: ……. Transportasi: ……... Kehilangan Pendapatan: …….. Lain-lain: ……	…… Hari 1. Ya 2. Tidak Total Biaya: ……

Biaya Pindah Tempat Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan	
30. Apakah Anda harus pindah untuk dapat menerima pengobatan TB ?	1. Ya 2. Tidak
a) Jika YA: Anda menyewa: ☐ Per Minggu ☐ Per Bulan ☐ Per Tahun	Biaya Sewa Rp ……..
Biaya Lain-lain Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan	
31. a) Apakah Anda membeli suplemen khusus untuk diet Anda dikarenakan penyakit TB, contohnya vitamin, daging, minuman berenergi, minuman ringan, buah-buahan, atau obat-obatan? *Jika Tidak, lanjut ke P32.*	1. Ya 2. Tidak 3. Tidak tahu/tidak jawab
b) Jika YA: Apakah jenisnya? (sebutkan) 1. Buah-buahan 2. Susu 3. Vitamin/Herbal 4. Daging 5. Lainnya (sebutkan):	
c) Berapa perkiraan biaya yang Anda keluarkan untuk membeli barang-barang tersebut dalam 30 hari terakhir?	……
32. a) Apakah Anda mengalami efek samping atau keluhan akibat minum obat TB selama pengobatan (MDR-)TB?	1. Ya 2. Tidak

(Efek samping adalah permasalahan kesehatan tambahan yang muncul selama pengobatan (MDR-) TB dan kemungkinan berhubungan dengan pengobatan) Jika Tidak, lanjut ke P33	
b) Jika YA: Apakah Anda sampai menghentikan minum obat TB karena keluhan tersebut dan butuh pengobatan untuk mengatasinya? *Termasuk perubahan regimen obat TB!*	1. Ya 2. Tidak
c) Jika YA, Berapa perkiraan biaya yang Anda keluarkan untuk membeli obat untuk mengatasi efek samping obat TB?	Total: Rp ……..…

Asuransi ***Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan***	
33. a) Apakah Anda memiliki asuransi kesehatan baik dari pemerintah maupun swasta? *Jika Tidak, lanjut ke P 34*	1. Ya 2. Tidak 3. Tidak tahu/tidak jawab
b) Jika YA: Tipe Asuransi? 1. BPJS Kesehatan (Penerima Bantuan Iuran) 2. BPJS Kesehatan (Ditanggung Institusi) 3. BPJS Kesehatan (Mandiri) 4. Asuransi Swasta (Reimbursement) 5. Asuransi Swasta (Tanpa Reimbursement)	
c) Apakah Anda telah mendapatkan penggantian biaya yang berkaitan dengan penyakit TB? *Cocokkan dengan P* ***Error! Reference source not found.*** *(tabel biaya pra-diagnosis & diagnosis) Jika Tidak, lanjut ke Poin 34*	1. Ya 2. Tidak
d) Jika ya, berapa jumlah penggantian biaya yang telah Anda terima? Untuk diagnosis: ……. Untuk pengobatan: ……. Untuk biaya transportasi:…… Lainnya: ……..	Total: ……..

Penyelesaian Masalah Keuangan ***Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan***	
34. Sejauh mana penyakit TB mempengaruhi kondisi keuangan keluarga?* *(lingkari)*	0 = tidak ada masalah 1 = kecil 2 = cukup serius 3 = serius 4 = sangat serius
35. a) jika Anda meminjam uang untuk membantu pembiayaan penyakit Anda, berapa jumlah uang yang Anda pinjam? *Jika Tidak meminjam, lanjut ke P36.* b) Kepada siapa Anda melakukan pinjaman (paling banyak)? *Lingkari yang paling sesuai*	Jumlah uang yang dipinjam: …….

1. Keluarga 2. Tetangga/Teman 3. Bank Swasta 4. Koperasi 5. Lainnya (sebutkan): ……	
c) Berapa besar bunga dari hutang tersebut? (%)	1. ….. % 2. Saya tidak membayar bunga. 3. Saya tidak diminta mengembalikan pinjaman uang tersebut.
36. a) Apakah Anda menjual properti Anda untuk membayar biaya dari penyakit TB? *Jika Tidak, lanjut ke P37.*	1. Ya 2. Tidak
b) Jika YA: Apa yang telah Anda jual? *Lingkari yang paling sesuai* 1. Tanah 2. Ternak 3. Alat Transportasi/Kendaraan 4. Alat rumah tangga 5. Hasil Pertanian 6. Lainnya (sebutkan): ……	
c) Berapa jumlah yang Anda dapatkan dari hasil penjualan properti Anda? Rp …….	
d) Apakah harga tersebut sesuai dengan harga pasaran? 1. Ya, sesuai harga pasar 2. Lebih rendah dari harga pasaran 3. Lebih tinggi dari harga pasaran	
e) Jika TIDAK: berapa perkiraan harga pasarannya? Rp ……	

Informasi Sosial-Ekonomi Situasi dan Pendapatan ***Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan***	
37. Siapa pencari nafkah utama dalam rumah tangga? 1. Pasien 2. Lainnya (sebutkan): …….	
38. Apakah Anda bekerja sebelum didiagnosis TB (termasuk pekerjaan non-formal)?	1. Ya 2. Tidak *(lanjut ke P 43)*
39. Bagaimana biasanya Anda digaji sebelum didiagnosis TB? 1. Digaji 2. Tidak menentu (misalnya, berdagang atau parkir) 3. Dibayar barang 4. Tidak dibayar 5. Lainnya	
40. Apakah Anda harus mengganti atau berhenti dari pekerjaan pada saat Anda mengidap TB?	1. Ya 2. Tidak
41. Bila Anda masih bekerja, berapa hari rata-rata Anda absen dari pekerjaan Anda dalam sebulan, pada 3 bulan terakhir, sejak Anda sakit TB	….. hari
Jika jawaban untuk P 41 adalah "1 hari" atau lebih: **42.** Apakah seseorang melakukan pekerjaan yang seharusnya Anda kerjakan?	1. Ya, anggota keluarga 2. Ya, orang lain 3. Tidak ada
43. Apakah ada orang lain yang melakukan pekerjaan rumah tangga Anda dan Anda membayarnya karena Anda mengidap TB? 1. Tidak 2. Ya, jumlah total (sampai sekarang)?	Jumlah Total: ……

44. a) Berapa anggota keluarga yang tinggal bersama Anda dalam satu rumah? b) Apakah ada seorang yang <u>khusus</u> tinggal di rumah Anda untuk mengurus Anda? *Jika TIDAK, lanjut ke P47* *Jika YA:* c) untuk berapa lama? d) Apakah mereka berhenti mencari nafkah untuk tinggal di rumah dan mengurus Anda? e) Apakah Anda membayar seseorang untuk mengurus Anda? Jika ya, berapa nilai tunai atau dalam nilai ?	..... orang 1. Ya 2. Tidak …… Minggu 1. Ya 2. Tidak 1. Ya 2. Tidak Total Nilai/Jumlah: …..
45. Apakah ada anggota keluarga (termasuk anak-anak atau anak di bawah usia sekolah) yang harus bekerja atau bekerja lebih untuk membayar biaya yang disebabkan karena penyakit TB?	1. Ya 2. Tidak
46. Apakah penyakit TB menyebabkan Anda kehilangan pekerjaan atau pendidikan? 1. Tidak sekolah 2. Kehilangan Pekerjaan 3. Putus Sekolah 4. Cuti di luar tanggungan 5. Cuti	

Pendapatan dan Pengeluaran Rumah Tangga ***Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan***	
47. Berapa perkiraan penghasilan rumah tangga Anda rata-rata per bulan SEBELUM mengidap TB ? (untuk seluruh anggota keluarga, termasuk pasien, untuk semua orang di rumah, termasuk pasien) 1. Pendapatan pasien : ……. 2. Pendapatan anggota rumah tangga lainnya: ……. 3. Jaminan kesejahteraan (klaim asuransi kecacatan, dll): ……. 4. Bantuan pemerintah: ……. 5. Lainnya: ……..…… TOTAL: ……	
48. Berapa perkiraan penghasilan rumah tangga Anda rata-rata per bulan SEKARANG ? 1. Pendapatan pasien : ……. 2. Pendapatan anggota rumah tangga lainnya: ……. 3. Jaminan kesejahteraan (klaim asuransi kecacatan, dll):: ……. 4. Bantuan pemerintah: ……. 5. Lainnya: ……..…… TOTAL: ……	
49. *Jika penghasilan di 47 berbeda dengan 48:* Apakah perubahan ini sebagai akibat dari penyakit TB?	1. Ya 2.Tidak

Indikator Sosial Ekonomi ***Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan***		
50. Apakah ada anggota keluarga yang saat ini memiliki aset berikut yang dapat digunakan ?	Isi dengan: 1. Ya 2. Tidak	Sebutkan perkiraan nilai dari kekayaan tersebut saat ini (diusahakan) Jika tidak dapat menyebutkan nilainya, sebutkan jenis, jumlah atau ukurannya

1. Mobil		
2. Sepeda motor		
3. Kulkas/ freezer		
4. AC		
5. Perhiasan emas		
6. Rumah		
7. Tanah		
8. Tanah pertanian		
9. Telepon / HP		
10. Saham perusahaan/Investasi		
11. Ternak		
12. Alat pertanian		
13. Bisnis non pertanian		
14. Daya listrik di rumah (Watt)		450 900 1300 2200 > 2200

Ada beberapa pertanyaan yang akan kami ajukan untuk dapat mengeksplorasi kebutuhan terhadap proteksi sosial bagi pasien TB dan keluarganya.

1. Pernahkah anda mendengar tentang proteksi sosial?
   a. Jika YA, apa yang Anda pahami dengan proteksi sosial? Apakah Anda dapat jelaskan?
   b. Jika TIDAK. Lanjut ke pertanyaan berikutnya.
2. Dengan biaya yang dikeluarkan untuk mendapatkan pengobatan TB, bagian biaya yang mana yang membuat Anda merasa mengalami kesulitan finansial dan berapa Rupiah yang Anda inginkan untuk dapat ditanggung oleh Pemerintah?

Lingkari yang paling dirasakan sulit oleh responden dan tuliskan berapa !

Kode	Jenis biaya	Biaya dalam Rp/Barang	Unit
A	Biaya konsultasi (bayar sendiri)		Per konsultasi
B	Obat-obatan (bayar sendiri)		Per bulan
C	Transportasi		Per kunjungan
D	Akomodasi		Per hari
E	Makanan, snack, minuman (saat kunjungan)		Per kunjungan
F	Makanan dan suplementasi		Jenis makanan atau suplementasi, per bulan
G	Kehilangan pendapatran atau biaya produktivitas		Per bulan
H	Biaya orang yang menemani		Per hari
I	Pengobatan penyakit lainnya (jika ada)		

3. Apakah Anda berpikir bahwa kondisi Anda yang terinfeksi TB berkaitan dengan kondisi tubuh, rumah dan lingkungan Anda? YA/TIDAK
   Jika TIDAK, wawancara selesai.
   Jika YA, Mohon pilih salah satu yang Anda anggap paling berkaitan! *Lingkari*

Kode	Kondisi
A	Makanan (tidak mampu memperoleh cukup makanan sehat
B	Tubuh (malnutrisi, akibat penyakit/kondisi lain)
C	Rumah (kurang ventilasi)
D	Tidak punya rumah
E	Lingkungan (kumuh, padat)

4. Apa yang Anda sarankan kepada Pemerintah untuk memecahkan masalah tersebut?

Terima kasih atas kerjasama Anda! Apakah ada yang ingin Anda tanyakan atau katakan?

……
……
……
……
……..

Komentar oleh pewawancara:
Antusiasme subyek :

0 1 2 3 4 5
Sama sekali tidak antusias Sangat antusias

……
……
……
……
……..

Tanggal dan Tanda tangan pewawancara
dd/mm/yy

…… ……

Annex C

Explanations of the Tool and guidance for researcher and interviewers

Penjelasan Kuesioner

Perangkat untuk memperkirakan biaya yang dikeluarkan pasien

No	Pertanyaan	Pilihan	Penjelasan
Pendahuluan			
	ID Responden	X – X – XX	Diisi kode (Provinsi) – (Kabupaten/Kota) – (Urutan ID Subyek, dari 01-xx)
	Nama Pewawancara		Jelas
	No Registrasi pasien di Fasilitas TB		No Rekam medik pasien. Dapat dikosongkan
	Tanggal wawancara (dd/mm/yy)		Jelas
	Nama provinsi		Jelas
	Nama Kabupaten/Kota		Jelas
	Nama Kelurahan		Jelas
	Tempat wawancara	Rumah/Nama fasilitas kesehatan	Jelas. Dapat diisi dengan nama Puskesmas atau RS jika dilakukan di Puskesmas atau RS
	Kategori fasilitas kesehatan tempat berobat	1. Puskesmas 2. Klinik swasta 3. RSUD/ Pemerintah 4. RS Swasta 5. RS lainnya, sebutkan.....	Tempat berobat utama saat ini atau saat diwawancara
	Apakah Anda memiliki pertanyaan? Apakah Anda akan berpartisipasi?	Ya / Tidak	Jelas
	Tanda tangan Responden		Responden dapat menandatangani di sini atau cukup di lembar informed consent di ampiran tersendiri
	Jika Tidak : alasan tidak berpartisipasi?	1. Tidak cakap berbahasa 2. Kendala waktu 3. Tidak nyaman 4. Lainnya, sebutkan……	Jelas
Informasi Pasien			
	Responden	1. Pasien 2. Pengawas Minum Obat (PMO) / wali yang tinggal di rumah tangga yang sama dengan pasien	Jelas PMO: Pengawas Minum Obat yang secara khusus ditunjuk oleh pasien/penyedia layanan
1	Jenis kelamin	1. Laki-laki 2. Perempuan	Jelas
	Usia	…. Tahun	Jelas

No	Pertanyaan	Pilihan	Penjelasan
2	Apakah pendidikan tertinggi Anda?	1. Tidak Sekolah 2. SD 3. SMP 4. SMA 5. Diploma 6. Sarjana 7. Pasca sarjana	Jelas
3	Tipe TB	1. Paru BTA + 2. Paru BTA - 3. Paru, tidak tahu status BTA 4. Ekstra Paru	Tanyakan apakah hasil pemeriksaan dahaknya positif atau negatif, dan apakah terkena tuberkulosis paru atau organ lain. Jika subyek tidak tahu, ragu-ragu, atau jawabannya tidak meyakinkan, lihat kartu berobat subyek atau tanyakan petugas setempat.
4	Regimen terapi	1. Kat I (penderita baru) 2. Kat II (terapi kambuh atau gagal) 3. Terapi MDR	Regimen pengobatan yang diterima subyek. Jika subyek tidak tahu, ragu-ragu, atau jawabannya tidak meyakinkan, lihat kartu berobat subyek atau tanyakan petugas setempat.
5	Fase terapi dan lama terapi	1. Intensif 2. Lanjutan	Tanyakan sudah bulan ke berapa berobat? Atau, warna apakah obat yang diterima (merah – intensif, kuning – lanjutan). Jika subyek tidak tahu, ragu-ragu, atau jawabannya tidak meyakinkan, lihat kartu berobat subyek atau tanyakan petugas setempat.
6	Status HIV	1. Positif 2. Negatif 3. Tidak dites 4. Tidak ada informasi	Lihat kartu berobat subyek atau tanyakan petugas setempat
7	Tanggal pemeriksaan dahak atau Foto toraks pertama (dd/mm/yy)		Jika subyek tidak tahu, ragu-ragu, atau jawabannya tidak meyakinkan, lihat kartu berobat subyek atau tanyakan petugas setempat.
8	Tanggal mulai pengobatan (dd/mm/yy)		Jika subyek tidak tahu, ragu-ragu, atau jawabannya tidak meyakinkan, lihat kartu berobat subyek atau tanyakan petugas setempat.
9	Berapa lama waktu yang diperlukan untuk mencapai tempat pengobatan Anda saat ini dari rumah Anda?		Jelas

No	Pertanyaan	Pilihan	Penjelasan
Pengobatan sebelumnya			
10a	Pernahkah Anda mendapatkan pengobatan TB sebelumnya?	1. Ya 2. Tidak	Jelas Jika subyek tidak tahu, ragu-ragu, atau jawabannya tidak meyakinkan, lihat kartu berobat subyek atau tanyakan petugas setempat. Konfirmasi dengan jawaban no 4.
10b	Jika YA: Apakah Anda menyelesaikan pengobatan TB Anda terdahulu?	1. Ya 2. Tidak	Jelas
10c	Jika TIDAK: Mengapa?	1. Kekurangan biaya untuk pengobatan 2. Efek samping obat 3. Jarak tempuh ke fasilitas kesehatan 4. Lainnya (sebutkan): ……	Pilih salah satu yang paling tepat atau mendekati.
11	Gejala apa yang Anda alami sehingga Anda memutuskan pergi berobat untuk penyakit Anda yang sekarang? Berapa lama Anda mengalami gejala-gejala tersebut sebelum Anda pergi mencari pengobatan?	1. Batuk 2. Keringat malam 3. Batuk berdarah 4. Berat badan turun 5. Lainnya	Tanyakan satu per satu dan contreng (YA/TIDAK) Jawab dalam minggu. - Jika subyek menjawab dalam HARI, gunakan ANGKA DESIMAL atau PECAHAN, misalnya 3/7 atau tuliskan X HARI - Jika subyek menjawab dalam bulan, kalikan jumlah bulan dengan 4 atau tuliskan XX BULAN
12	Ke mana saja Anda mencari pengobatan untuk mengatasi gejala-gejala tersebut?	1. RSUD 2. RS Swasta 3. Puskesmas 4. Klinik Swasta **5.** Lainnya	Tanyakan satu per satu dan contreng (YA/TIDAK)
	Ke mana Anda pergi pertama kali? Lingkari tempat pertama pengobatan tersebut di atas		Lingkari NOMOR PILIHAN di POIN 12 yang disebutkan subyek sebagai tempat pertama subyek berobat
13	*Jika selain dari fasilitas kesehatan pemerintah yang dipilih di 12):*	8. Jarak terlalu jauh 9. Biaya terlalu mahal 10. Waktu tunggu terlalu lama	Pilih salah satu yang paling tepat atau mendekati.

No	Pertanyaan	Pilihan	Penjelasan
	Mengapa Anda tidak pergi ke fasilitas kesehatan pemerintah, seperti Puskesmas atau RSUD, ketika Anda pertama kali ingin berobat? Lingkari yang paling sesuai.	11. Fasilitas tidak lengkap/tersedia 12. Tidak percaya pada kualitas fasilitas kesehatan pemerintah 13. Tidak ada obat-obatan tersedia **14.** Lainnya (Jelaskan)	
14	Berapa banyak biaya yang Anda habiskan untuk setiap kunjungan sebelum Anda didiagnosis TB, termasuk kunjungan ketika Anda benar-benar menerima diagnosis Anda?		*Untuk pasien MDR-TB, tanyakan hanya tentang biaya untuk diagnosis MDR-TB; untuk pasien TB lainnya, tanyakan tentang biaya untuk diagnosis TB. Untuk semua yang tidak berhubungan, tandai dengan N/A, isi satu baris per kunjungan.* *Untuk pertanyaan biaya, bila pasien tidak bisa menjawab, tulis "tidak tahu". Jangan hanya dikosongkan*
	Penyedia Layanan :	1. RSUD 2. RS Swasta 3. Puskesmas 4. Klinik Swasta 5. Lainnya, misalnya klinik alternatif, dukun, mantri, bidan, dsb	Diurut dari pertama kali subyek berobat ketika mengalami keluhan yang dijawab di POIN 11 SELF MEDICATION atau beli obat sendiri tidak dimasukkan.
	Total Waktu (bolak balik)		
	Biaya administrasi		Dalam jam. Jelas
	Biaya Tes Lab		Biaya pendaftaran, konsultasi dokter (di luar biaya obat-obatan).
	Biaya Foto toraks		Untuk tes dahak atau darah, bukan Foto toraks
	Biaya Obat-obatan		Khusus untuk Foto toraks Khusus untuk biaya obat-obatan
	Biaya perjalanan		Jika subyek tidak dapat membedakan item biaya antara administrasi, tes lab, Foto toraks, dan obat-obatan, TOTAL BIAYA

No	Pertanyaan	Pilihan	Penjelasan
	Biaya makan Biaya akomodasi Sub-Total biaya tiap kunjungan		dapat dijadikan satu di ITEM BIAYA ADMINISTRASI Biaya Total Perjalanan pulang pergi, termasuk ke Lab, Foto toraks (jika di tempat yang berbeda). Jika menggunakan kendaraan pribadi (motor/mobil), tuliskan biaya Parkir dan sejenisnya (jika ada) Biaya makan yang dikeluarkan ketika subyek pergi ke fasilitas kesehatan, misalnya mengemil atau makan siang (jika ada) Biaya menginap jika subyek harus pergi ke tempat yang jauh dan menginap Dijumlahkan per setiap kunjungan. Dapat dikosongkan dan dihitung secara otomatis pada saat analisis.
	Kehilangan penghasilan pasien Reimbursement asuransi Diantar oleh orang lain Biaya perjalanan untuk pengantar Biaya akomodasi untuk pengantar Kehilangan pendapatan yang dialami pengantar	Dalam rupiah Ya / Tidak	Jika subyek - Dipotong gaji ketika absen bekerja - Kehilangan potensi pendapatan ketika tidak bekerja informal, misalnya berdagang atau buruh harian Jika subyek memiliki asuransi (swasta atau perusahaan) dan pengeluaran untuk berobatnya diganti oleh asuransi/perusahaan Jika subyek diantar oleh orang lain yang merupakan anggota keluarga Biaya Total Perjalanan pulang pergi pengantar, termasuk ke Lab, Foto toraks (jika di tempat yang berbeda). Jika menggunakan kendaraan pribadi (motor/mobil), tuliskan biaya Parkir dan sejenisnya (jika ada)

No	Pertanyaan	Pilihan	Penjelasan
			Biaya menginap jika pengantar harus pergi ke tempat yang jauh dan menginap Jika pengantar - Dipotong gaji ketika absen bekerja - Kehilangan potensi pendapatan ketika tidak bekerja informal, misalnya berdagang atau buruh harian
	Total Biaya Pra-Diagnosis dan Diagnosis dikurangi Biaya diganti asuransi		Dapat dikosongkan dan dihitung secara otomatis pada saat analisis.
Biaya Pengobatan			
15	Seberapa sering Anda pergi ke fasilitas kesehatan untuk mengambil obat TB Anda? a. Fase intensif b. Fase lanjutan	 …. Kali/bulan …. Kali/bulan	- Jika subyek datang setiap hari untuk mengambil obat dan makan obat di fasilitas kesehatan, tuliskan 30 - Jika subyek datang hanya untuk mengambil obat dan memakan obat di rumah, tuliskan berapa kali subyek mengambil obat ke fasilitas kesehatan
16	Berapa lama waktu yang Anda butuhkan untuk sampai ke tempat tersebut (sekali perjalanan)?		Cukup isi MENIT pada MODA (pilih: jalan kaki, kendaraan pribadi, angkutan umum) yang paling sering dilakukan
17	Berapa rata-rata total waktu yang dibutuhkan untuk sekali kunjungan, termasuk waktu perjalanan dan waktu tunggu (total waktu hingga selesai)?		Jelas
18	Dari rumah ke fasilitas kesehatan, berapa biaya transportasi yang Anda keluarkan? (pulang pergi)		Biaya Total Perjalanan pulang pergi pengantar. Jika menggunakan kendaraan pribadi (motor/mobil), tuliskan biaya Parkir, tol, dan sejenisnya (jika ada)
19	Jika Anda pergi ke fasilitas kesehatan untuk mengambil obat Anda, berapa biaya yang Anda keluarkan untuk makanan dan minuman pada hari tersebut?		Biaya makan yang dikeluarkan ketika subyek pergi ke fasilitas kesehatan, misalnya mengemil atau makan siang (jika ada)

No	Pertanyaan	Pilihan	Penjelasan
20a	Apakah Anda harus membayar biaya administrasi pada saat mengambil obat TB?	Ya / Tidak	Biaya administrasi pendaftaran atau biaya konsultasi dokter
20b	Jika YA, berapa?		Jelas
21a	Apakah ada biaya akomodasi yang harus Anda tanggung saat mengambil obat TB Anda?		Biaya menginap jika subyek harus pergi ke tempat yang jauh dan menginap
21b	Jika YA, berapa?		Jelas
22	Apakah Anda pernah menjalani pemeriksaan/tes untuk evaluasi pengobatan sejak pengobatan dimulai? *Jika TIDAK, lanjut ke P 23.*	1. Sputum / tes lab 2. Foto toraks 3. Pemeriksaan lain	Pemeriksaan yang dilakukan SETELAH subyek mendapat pengobatan TB. Tanyakan satu per satu.
Biaya yang dikeluarkan untuk pengantar			
23a	Apakah ada yang menemani Anda pada waktu mengambil obat dan melakukan pemeriksaan laboratorium/ Foto toraks lanjutan, atau menggantikan Anda untuk mengambilkan obat Anda? *Jika tidak, lanjut ke P 244*	Ya / Tidak	Jelas
23b	Jika YA, Apakah orang tersebut kehilangan pendapatannya karena pergi menemani Anda? Jika Ya, berapa jumlah total	Ya / Tidak	Jika pengantar - Dipotong gaji ketika absen bekerja - Kehilangan potensi pendapatan ketika tidak bekerja informal, misalnya berdagang atau buruh harian Jelas
23c	*Jika YA ,* berapa kali orang tersebut menemani atau menggantikan Anda?		Jelas
Rawat Inap			
24	Apakah Anda pernah dirawat sebelumnya (karena TB) atau selama pengobatan TB Anda? *Jika TIDAK, lanjut ke P30.*	Ya / Tidak	Dirawat di RS atau Puskesmas: - Yang dalam perawatannya kemudian ditemukan atau didiagnosis TB - Perawatan pada masa pengobatan yang terkait TB - Jika perawatan tidak terkait TB, misalnya usus buntu, DBD, atau

No	Pertanyaan	Pilihan	Penjelasan
			kecelakaan saja, DIANGGAP TIDAK
25	Jika YA: berapa hari Anda dirawat di rumah sakit atau Puskesmas?		Jelas
26	Berapa biaya yang Anda keluarkan selama dirawat di rumah sakit atau Puskesmas?		Biaya untuk perawatan. Tulis ANGKA 0 jika ditanggung oleh asuransi (BPJS, swasta, atau perusahaan)
27	Apakah ada keluarga / teman yang menemani Anda selama di rumah sakit? *Jika Tidak, lanjut ke P30.*	Ya / Tidak	Jelas
28	Jika YA: Berapa hari ia tinggal bersama Anda (menginap di rumah sakit)?	... Hari	Jelas
29	Apakah ada biaya lain yang dikeluarkan untuk keluarga/teman Anda selama tinggal di rumah sakit? Akomodasi (RS atau lainnya) Makanan Transportasi Kehilangan pendapatan Lain-lain	Ya / Tidak	Jelas Jika harus membayar penginapan, rumah singgah, dan sejenisnya Makan siang dan/atau cemilan selama menunggu pasien Transportasi bolak-balik, parkir, tol, dan sejenisnya Jika anggota keluarga - Dipotong gaji ketika absen bekerja - Kehilangan potensi pendapatan ketika tidak bekerja informal, misalnya berdagang atau buruh harian Lain-lain (jika ada) Masing-masing ITEM DIJUMLAHKAN sesuai jumlah orang yang menemani dan jumlah hari menemani
Biaya Pindah Tempat			
30	Apakah Anda harus pindah untuk dapat menerima pengobatan TB ?	Ya / Tidak	Misalnya, subyek harus mengontrak di sekitar fasilitas kesehatan atau pindah ke rumah sanak keluarga yang dekat dengan fasilitas kesehatan

No	Pertanyaan	Pilihan	Penjelasan
30a	Jika YA: Anda menyewa	1. Per Minggu 2. Per Bulan 3. Per Tahun	Tulis ANGKA 0 subyek tidak mengeluarkan biaya, misalnya pindah ke rumah keluarga
Biaya Lain-lain			
31a	Apakah Anda membeli suplemen khusus untuk diet Anda dikarenakan penyakit TB, contohnya vitamin, daging, minuman berenergi, minuman ringan, buah-buahan, atau obat-obatan? *Jika Tidak, lanjut ke P32.*	1. Ya 2. Tidak 3. Tidak tahu/Tidak jawab	Suplemen yang HANYA DIBELI ketika melakukan pengobatan TB
31b	Jika YA: Apa jenisnya?	1. Buah-buahan 2. Susu 3. Vitamin/Herbal 4. Daging 5. Lainnya (sebutkan)	Jelas Jelas Termasuk vitamin dari dokter Jelas Tuliskan, misalnya jamu, madu, dll
31c	Berapa perkiraan biaya yang Anda keluarkan untuk membeli barang-barang tersebut dalam 30 hari terakhir?		Jelas
32a	Apakah Anda mengalami efek samping atau keluhan akibat minum obat TB selama pengobatan (MDR-)TB? *Jika Tidak, lanjut ke P33*	Ya / Tidak	*Efek samping adalah permasalahan kesehatan tambahan yang muncul selama pengobatan (MDR-) TB dan kemungkinan berhubungan dengan pengobatan*
32b	Jika YA: Apakah Anda sampai menghentikan minum obat TB karena keluhan tersebut dan butuh pengobatan untuk mengatasinya? *Termasuk perubahan regimen obat TB!*		Jelas
32c	Jika YA, Berapa perkiraan biaya yang Anda keluarkan untuk membeli obat untuk mengatasi efek samping obat TB?		Jelas
Asuransi			
33a	Apakah Anda memiliki asuransi kesehatan baik dari pemerintah maupun swasta? *Jika Tidak, lanjut ke P 34*	Ya / Tidak	Jelas

No	Pertanyaan	Pilihan	Penjelasan
33b	Jika YA: Tipe asuransi?	1. BPJS Kesehatan (Penerima Bantuan Iuran) 2. BPJS Kesehatan (Ditanggung Institusi) 3. BPJS Kesehatan (Mandiri) 4. Asuransi Swasta (Reimbursement) 5. Asuransi Swasta (Tanpa Reimbursement)	Jelas
33c	Apakah Anda telah mendapatkan penggantian biaya yang berkaitan dengan penyakit TB? *Cocokkan dengan P* **Error! Reference source not found.** *(tabel biaya pra-diagnosis & diagnosis) Jika Tidak, lanjut ke Poin 34*	Ya / Tidak	Termasuk voucher transport dari Program TB
33d	Jika ya, berapa jumlah penggantian biaya yang telah Anda terima? Untuk diagnosis: ……. Untuk pengobatan: ……. Untuk biaya transportasi:…… Lainnya: ……..		Jika subyek tidak dapat memilah per item, tulis jumlah penggantian biaya secara keseluruhan.
Penyelesaian masalah keuangan			
34	Sejauh mana penyakit TB mempengaruhi kondisi keuangan keluarga?* *(lingkari)*	0 = tidak ada masalah 1 = kecil 2 = cukup serius 3 = serius 4 = sangat serius	Berikan penjelasan terlebih dahulu antara 0-4 dan persilakan subyek memilih. Jika subyek bingung dalam memilih, berikan PILIHAN yang mendekati. Misalnya, ”Apakah maksud Ibu: Cukup serius?”
35a	Jika Anda meminjam uang untuk membantu pembiayaan penyakit Anda, berapa jumlah uang yang Anda pinjam? *Jika Tidak meminjam, lanjut ke P36.*		Kosongkan atau beri Tanda X jika subyek tidak melakukan pinjaman Jika melakukan pinjaman LEBIH DARI SATU KALI, tulis total pinjamannya
35b	Kepada siapa Anda melakukan pinjaman (paling banyak)? *Lingkari yang paling sesuai*	1. Keluarga 2. Tetangga/Teman 3. Bank Swasta 4. Koperasi 5. Lainnya (sebutkan):	Pilih yang paling sesuai atau paling banyak

No	Pertanyaan	Pilihan	Penjelasan
35c	Berapa besar bunga dari hutang tersebut? (%)	1. ….. % 2. Saya tidak membayar bunga. 3. Saya tidak diminta mengembalikan pinjaman uang tersebut.	Jelas
36a	Apakah Anda menjual properti Anda untuk membayar biaya dari penyakit TB? *Jika Tidak, lanjut ke P37.*	Ya / Tidak	Menjual untuk keperluan pengobatan TB, bukan karena masalah keuangan lain, misalnya hutang, dsb
36b	Jika YA**:** Apa yang telah Anda jual? *Lingkari yang paling sesuai*	1. Tanah 2. Ternak 3. Alat transportasi/ Kendaraan 4. Alat rumah tangga 5. Hasil Pertanian 6. Lainnya (sebutkan):	Jelas
36c	Berapa jumlah yang Anda dapatkan dari hasil penjualan properti Anda?		Jelas
36d	Apakah harga tersebut sesuai dengan harga pasaran?	1. Ya, sesuai harga pasaran 2. Lebih rendah dari harga pasaran 3. Lebih tinggi dari harga pasaran	Jelas
36e	Jika TIDAK: berapa perkiraan harga pasarannya?		Biarkan subyek menjawab sendiri terlebih dahulu. Jika subyek tidak tahu atau bingung menjawab, berikan pilihan (*challenge*). Misalnya, ”Apakah sekitar 2 juta?”
Informasi Sosial-Ekonomi			
37	Siapa pencari nafkah utama dalam rumah tangga?	1. Pasien 2. Lainnya (sebutkan)	Pencari nafkah utama, yang bekerja dan penghasilannya paling besar untuk menutupi kebutuhan rumah tangga
38	Apakah Anda bekerja sebelum didiagnosis TB (termasuk pekerjaan non-formal)?	Ya / Tidak	Pekerjaan yang mendapatkan gaji atau dibayar
39	Bagaimana biasanya Anda digaji sebelum didiagnosis TB?	1. Digaji 2. Tidak menentu (misalnya, berdagang atau parkir) 3. Dibayar barang 4. Tidak dibayar	Pensiunan dimasukkan dalam lainnya

No	Pertanyaan	Pilihan	Penjelasan
		5. Lainnya	
40	Apakah Anda harus mengganti atau berhenti dari pekerjaan pada saat Anda mengidap TB?	Ya / Tidak	Jelas
41	Bila Anda masih bekerja, berapa hari rata-rata Anda absen dari pekerjaan Anda dalam sebulan, pada 3 bulan terakhir, sejak Anda sakit TB?	… Hari	Jelas
42	*Jika jawaban untuk P 41 adalah "1 hari" atau lebih:* Apakah seseorang melakukan pekerjaan yang seharusnya Anda kerjakan?	1. Ya, anggota keluarga 2. Ya, orang lain 3. Tidak ada	Jelas
43	Apakah ada orang lain yang melakukan pekerjaan rumah tangga Anda dan Anda membayarnya karena Anda mengidap TB?	1. Tidak 2. Ya, jumlah total (sampai sekarang)	Jelas
44a	Berapa anggota keluarga yang tinggal bersama Anda dalam satu rumah?		Jelas
44b	Apakah ada seorang yang <u>khusus</u> tinggal di rumah Anda untuk mengurus Anda? *Jika TIDAK, lanjut ke P47*	Ya / Tidak	Orang yang ditunjuk khusus untuk merawat pasien
44c	*Jika YA:* untuk berapa lama?	... Minggu	Jelas
44d	Apakah mereka berhenti mencari nafkah untuk tinggal di rumah dan mengurus Anda?	Ya / Tidak	Jelas
44e	Apakah Anda membayar seseorang untuk mengurus Anda? Jika ya, berapa nilai tunai atau dalam nilai ?	Ya / Tidak ….. (Rp)	KHUSUS jika ada orang yang DIBAYAR
45	Apakah ada anggota keluarga (termasuk anak-anak atau anak di bawah usia sekolah) yang harus	Ya / Tidak	Karena subyek sakit, maka apakah ada orang lain yang HARUS BEKERJA?

No	Pertanyaan	Pilihan	Penjelasan
	bekerja atau bekerja lebih untuk membayar biaya yang disebabkan karena penyakit TB?		
46	Apakah penyakit TB menyebabkan Anda kehilangan pekerjaan atau pendidikan?	1. Tidak 2. Kehilangan Pekerjaan 3. Putus Sekolah 4. Cuti di luar tanggungan 5. Cuti sekolah	Pensiunan dimasukkan kategori TIDAK
Pendapatan dan Pengeluaran Rumah Tangga			
47	Berapa perkiraan penghasilan rumah tangga Anda rata-rata per bulan SEBELUM mengidap TB ? (untuk seluruh anggota keluarga, termasuk pasien, untuk semua orang di rumah, termasuk pasien)	1. Pendapatan pasien : 2. Pendapatan anggota rumah tangga lainnya: 3. Jaminan kesejahteraan (klaim asuransi kecacatan, dll): 4. Bantuan pemerintah: 5. Lainnya: TOTAL:	Pendapatan pasien per bulan. Jika tidak menentu, hitung: JUMLAH HARI KERJA X (RERATA) PENDAPATAN PER HARI Idem. Jumlahkan untuk semua anggota rumah tangga yang mendapatkan penghasilan Jika ada bentuk Santunan dari Pemerintah/Yayasan yang bersifat regular, misalnya, BLT. KJP, KIS, BPJS, tidak termasuk. Pemasukan lain, misalnya "Diberikan rutin oleh anak, per bulan" Dikosongkan saja.
48	Berapa perkiraan penghasilan rumah tangga Anda rata-rata per bulan SEKARANG ?	1. Pendapatan pasien : 2. Pendapatan anggota rumah tangga lainnya: 3. Jaminan kesejahteraan (klaim asuransi kecacatan, dll): 4. Bantuan pemerintah: 5. Lainnya: TOTAL:	Pendapatan pasien per bulan. Jika tidak menentu, hitung: JUMLAH HARI KERJA X (RERATA) PENDAPATAN PER HARI Idem. Jumlahkan untuk semua anggota rumah tangga yang mendapatkan penghasilan Jika ada bentuk Santunan dari Pemerintah/Yayasan yang bersifat regular, misalnya, BLT. KJP, KIS, BPJS, tidak termasuk. Pemasukan lain, misalnya "Diberikan rutin oleh anak, per bulan" Dikosongkan saja.
49	*Jika penghasilan di 47 berbeda dengan 48:*	Ya / Tidak	Tanyakan kepada subyek

No	Pertanyaan	Pilihan	Penjelasan
	Apakah perubahan ini sebagai akibat dari penyakit TB?		
Indikator Sosial Ekonomi			
50	Apakah ada anggota keluarga yang saat ini memiliki aset berikut yang dapat digunakan ?	Ya / Tidak	Sebutkan perkiraan nilai dari kekayaan tersebut saat ini (diusahakan) Jika tidak dapat menyebutkan nilainya, sebutkan jenis, jumlah atau ukurannya
	15. Mobil 16. Sepeda motor 17. Kulkas/ freezer 18. AC 19. Perhiasan emas 20. Rumah 21. Tanah 22. Tanah pertanian 23. Telepon / HP 24. Saham perusahaan/Investasi 25. Ternak 26. Alat pertanian 27. Bisnis non pertanian 28. Daya listrik di rumah (Watt)	450 900 1300 2200 > 2200	Jika tidak tahu daya watt-nya, LIHAT barang elektronik yang ada di rumah. Jika ada AC, diasumsikan ≥1300. Jika mendapat subsidi (tidak bayar), diasumsikan 450.
Pertanyaan tambahan			
1	Pernahkah Anda mendengar tentang proteksi sosial?	Ya / Tidak	Jelas
	a. Jika Ya, apa yang Anda pahami dengan proteksi sosial? Apakah Anda dapat jelaskan? b. Jika TIDAK. Lanjut pertanyaan berikutnya		Jelas
2	Dengan biaya yang dikeluarkan untuk mendapatkan pengobatan TB, bagian biaya yang mana yang membuat Anda merasa mengalami kesulitan finansial dan berapa Rupiah yang Anda	1. Biaya konsultasi (bayar sendiri) 2. Obat-obatan (bayar sendiri) 3. Transportasi 4. Akomodasi	Biarkan subyek menjawab sendiri terlebih dahulu. Jika subyek merasa tidak ada yang perlu ditanggung, KOSONGKAN. Jika subyek bingung, berikan pertanyaan satu per satu dan

No	Pertanyaan	Pilihan	Penjelasan
	inginkan untuk dapat ditanggung oleh Pemerintah?	5. Makanan, snack, minuman (saat kunjungan) 6. Makanan dan suplementasi 7. Kehilangan pendapatran atau biaya produktivitas 8. Biaya orang yang menemani 9. Pengobatan penyakit lainnya (jika ada)	dijawab (Ya/Tidak), kemudian sebutkan jumlah yang menurut subyek perlu ditanggung. Upayakan bertanya ITEM yang TERLIHAT MEMBERATKAN pada pertanyaan-pertanyaan sebelumnya terlebih dahulu. Misalnya, subyek mengeluarkan biaya transport besar, sedangkan tidak mengeluarkan biaya makan. Maka, tanyakan ”Apakah biaya transportasi perlu ditanggung?”, bukan biaya makan
Penutup			
	Terima kasih atas kerjasama Anda! Apakah ada yang ingin Anda tanyakan atau katakan?		Jelas
	Komentar oleh pewawancara		
	Antusiasme subyek	0 Sama sekali tidak antusias 1 2 3 4 5 Sangat antusias	Jelas. Pilih salah satu
		……..	Diisi jika ada komentar khusus lainnya.
			Jelas

Annex D

Reasons for not choosing public facilities at the first contact

Reason	Urban		Sub-urban		Rural		Total	
	n	(%)	n	(%)	n	(%)	n	(%)
Distance to facility	7	(21)	10	(25)	15	(30)	32	(26)
Accustomed to private facility	4	(12)	7	(18)	14	(28)	25	(20)
Mistrust towards public facility	4	(12)	5	(13)	4	(8)	13	(11)
No public facility available	2	(6)	4	(10)	5	(10)	11	(9)
Long waiting time	4	(12)	2	(5)	1	(2)	7	(6)
Did not know PHC offered free TB service	1	(3)	1	(3)	5	(10)	7	(6)
Assumed patient had common cough, not TB	3	(9)	0	(0)	2	(4)	5	(4)
No answer	3	(9)	2	(5)	0	(0)	5	(4)
PHC had limited working hours	1	(3)	1	(3)	1	(2)	3	(2)
Others	4	(12)	8	(20)	3	(6)	15	(12)

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Annex E

Average pre-diagnostic costs according to the patient's first point of contact, in USD, mean (95% CI)

	Direct Medical Costs	*P*	Travel costs	*P*	Food costs	*P*	Total costs	*P*
PHC	5.4 (3.3-7.4)		1.8 (1.2-2.4)		0.6 (0.4-0.8)		14 (10-17)	
Private clinics	21.4 (14.6-28.1)	<0.001	2.7 (1.8-3.5)	0.087	0.7 (0.4-1.0)	0.424	32 (23-41)	<0.001
Public hospitals	8.9 (3.4-14.4)	0.408	2.5 (1.5-3.4)	0.274	1.1 (0.5-1.7)	0.094	18 (9-27)	0.376
Private hospitals	32.4 (17.3-47.5)	<0.001	2.6 (0.7-4.5)	0.180	0.7 (-0.2-1.6)	0.580	37 (22-52)	0.001
Others	12.1 (2.1-22.2)	0.366	2.1 (0.6-3.6)	0.725	0.3 (-0.1-0.6)	0.630	18 (7-29)	0.586

Annex F

The incidence of catastrophic costs if patients received 90%, 80%, 70% and 60% of the potential cash transfer.

Simulated hypothetical scenario	Incidence of catastrophic costs if patients received X percent of potential cash transfer, % (95% *CI*)				
	100%	90%	80%	70%	60%
TB					
Baseline (no cash transfer)	36 (31–42)	-	-	-	-
Transportation costs	28 (23–33)	29 (25–35)	30 (25–35)	30 (25–36)	32 (27–37)
Food–supplement costs	26 (21–30)	26 (22–31)	26 (21–31)	27 (22–32)	27 (23–32)
Income loss[a]	26 (21–30)	27 (22–31)	28 (23–33)	30 (25–35)	31 (26–36)
Income loss[b]	17 (13–21)	18 (14–23)	20 (16–25)	23 (18–27)	25 (20–30)
Transportation costs and income loss	17 (13–22)	19 (14–23)	21 (17–26)	22 (18–27)	26 (22–30)
Food-supplement costs and income loss	16 (12–20)	18 (14–22)	18 (14–23)	20 (16–25)	22 (17–27)
Transportation, food supplement, and income loss	11 (8–15)	12 (9–15)	14 (10–18)	16 (12–20)	19 (15–23)
MDR-TB					
Baseline (no cash transfer)	83 (73–92)	-	-	-	-
Transportation costs	59 (47–71)	63 (50–74)	67 (56–78)	69 (57–81)	73 (64–84)
Food-supplement costs	77 (65–87)	78 (68–88)	78 (68–88)	78 (68–88)	78 (68–88)
Income loss[a]	58 (46–70)	63 (51–74)	67 (55–79)	73 (62–85)	73 (63–84)
Income loss[b]	52 (39–65)	56 (44–68)	61 (49–73)	69 (57–81)	69 (58–80)
Transportation costs and income loss	28 (18–40)	33 (22–44)	38 (27–50)	47 (35–59)	53 (42–66)
Food-supplement costs and income loss	53 (41–66)	55 (42–67)	63 (51–75)	64 (52–76)	70 (60–81)
Transportation, food supplement, and income loss	23 (13–35)	31 (20–42)	34 (23–47)	38 (26–49)	47 (36–60)

[a] The hypothetical cash transfer was assumed to have been delivered to TB patients who had experienced job loss, [b] The hypothetical cash transfer was assumed to have been delivered to TB patients who had experienced any income loss regardless of whether or not they had experienced job loss.

Annex G

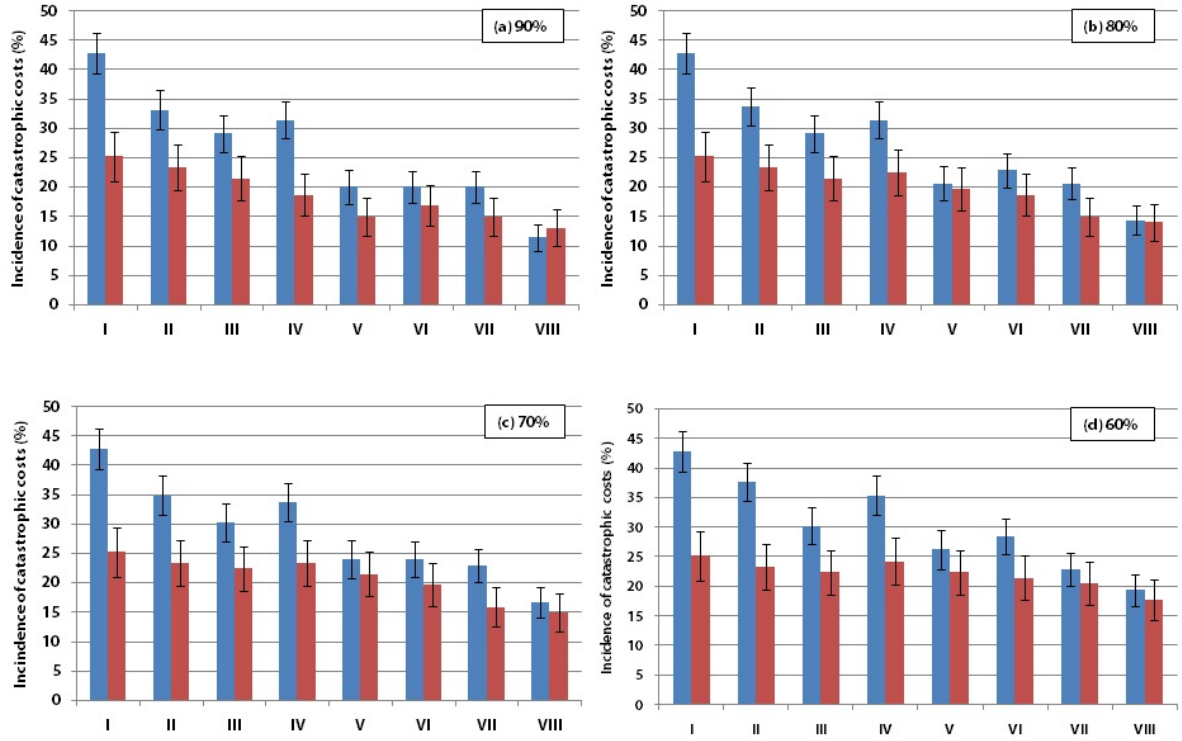
P values for the differences in catastrophic costs between scenarios.

	Simulated hypothetical scenario	% (95% *CI*)	*P*-values for difference between scenarios						
			I	II	III	IV	V	VI	VII
TB									
I	Baseline (no cash transfer)	36 (31–42)							
II	Transportation costs	28 (23–33)	< 0.001						
III	Food-supplement costs	26 (21–30)	< 0.001	0.092					
IV	Income loss[a]	26 (21–30)	< 0.001	0.371	1				
V	Income loss[b]	17 (13–21)	< 0.001	< 0.001	0.001	< 0.001			
VI	Transportation costs and income loss	17 (13–22)	< 0.001	< 0.001	< 0.001	< 0.001	1		
VII	Food-supplement costs and income loss	16 (12–20)	< 0.001	< 0.001	< 0.001	< 0.001	0.711	0.454	
VIII	Transportation, food supplement, and income loss	11 (8–15)	< 0.001	< 0.001	< 0.001	< 0.001	0.004	< 0.001	< 0.001
MDR-TB									
I	Baseline (no cash transfer)	83 (73–92)							
II	Transportation costs	59 (47–71)	< 0.001						
III	Food-supplement costs	77 (65–87)	0.125	0.001					
IV	Income loss[a]	58 (46–70)	< 0.001	1	0.008				
V	Income loss[b]	52 (39–65)	< 0.001	0.383	0.001	0.125			
VI	Transportation costs and income loss	28 (18–40)	< 0.001	< 0.001	< 0.001	< 0.001	0.001		
VII	Food-supplement costs and income loss	53 (41–66)	< 0.001	0.481	< 0.001	0.25	1	< 0.001	
VIII	Transportation, food supplement, and income loss	23 (13–35)	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001

[a] The hypothetical cash transfer was assumed to have been delivered to TB patients who had experienced job loss, [b] The hypothetical cash transfer was assumed to have been delivered to TB patients who had experienced any income loss regardless of whether or not they had experienced job loss.

Annex H

The incidence of catastrophic costs between poor and non-poor if TB patients received 90%, 80%, 70% and 60% of the potential cash transfers



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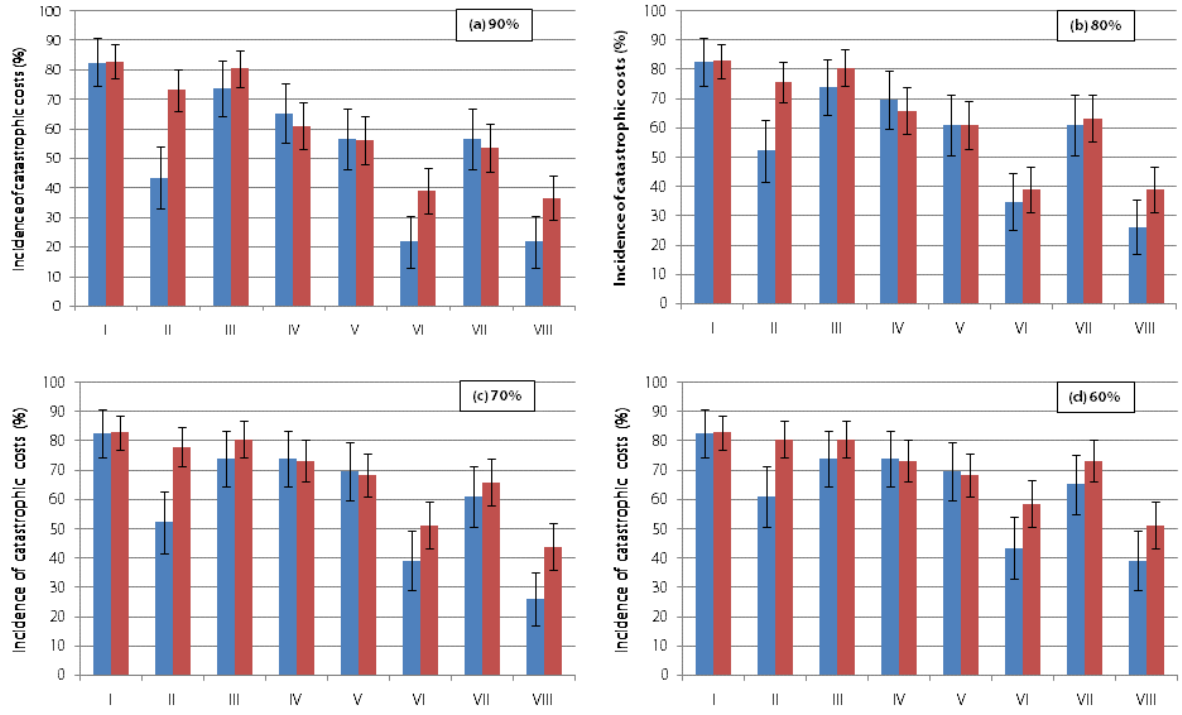
Annex I

The incidence of catastrophic costs between poor and non-poor if MDR-TB patients received 90%, 80%, 70% and 60% of the potential cash transfers



Fuady et al. *Infectious Diseases of Poverty* (2019) 8:10

List of Publications

Articles in this PhD project

1. Ahmad Fuady, Tanja A.J. Houweling, Muchtaruddin Mansyur, Jan Hendrik Richardus. *Adaptation of the Tool to Estimate Patient Costs Questionnaire into Indonesian Context for Tuberculosis-affected Households.* Actamedica Indonesiana 2018;50(1): 3-10.
2. Ahmad Fuady, Tanja A.J. Houweling, Muchtaruddin Mansyur, Jan Hendrik Richardus. *Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of universal health coverage.* Infectious Diseases of Poverty. 2018;7(1): 3.
3. Ahmad Fuady, Tanja A.J. Houweling, Muchtaruddin Mansyur, Erlina Burhan, Jan Hendrik Richardus. *Cost of seeking care for tuberculosis since the implementation of universal health coverage in Indonesia.* (In review)
4. Ahmad Fuady, Tanja A.J. Houweling, Muchtaruddin Mansyur, Erlina Burhan, Jan Hendrik Richardus. *Catastrophic costs due to tuberculosis worsen treatment outcomes: a prospective cohort study in Indonesia.* (In review)
5. Ahmad Fuady, Tanja A.J. Houweling, Muchtaruddin Mansyur, Erlina Burhan, Jan Hendrik Richardus. *Effect of financial support on reducing the incidence of catastrophic costs among tuberculosis-affected households in Indonesia: eight simulated scenarios.* Infectious Diseases of Poverty. 2019 **8**:10

Articles in other projects

1. Soumyava Basu, Rina La Distia Nora, Narsing A Rao, Xuejuan Jiang, Ahmad Fuady. *Prognostic factors for TB-associated uveitis in the Asia-Pacific Region: results of a modified Delphi survey.* Eye. 2020. doi:10.1038/s41433-019-0743-1.
2. Boy Subirosa Sabarguna, Ahmad Fuady. *Prospective e-library at the faculty of medicine*. Advanced Science Letters. 2017; 23(4): 3733-7.
3. Prima Almazini, Bambang Budi Siswanto, Markus Meyer, Mardiati Nadjib, Isman Firdaus, Ahmad Fuady, Paola Antonini, Salvatore Di Somma. *An health economic evaluation of using N-terminal pro brain natriureticpeptide for the management of acute heartfailure: a pilot study in Indonesian tertiary referral hospital*. Emergency Care Journal 2019; 15:7919.
4. Ibrahim Agung, Nyoman Murdana, Ruliando Hasea Purba, Ahmad Fuady. *Low-level laser therapy and dry needling for myofascial pain syndrome of the upper trapezius muscle: an interventional study.* IOP Conf. Series: Journal of Physics: Conf. Series 1073 (2018) 062045.

Books and Book Chapters

1. Ahmad Fuady. *Arsitektur jaminan kesehatan Indonesia: capaian, kritik dan tantangan masa depan*. Jakarta: Sagung Seto. 2019.
2. Endang Basuki, Ahmad Fuady, Sylvia D. Elvira. *Komunikasi dalam penanganan masalah tuberculosis*. In: Mora Claramita, Astrid P Susilo, Marcy Rosenbaum, Jan van Dalen. Komunikasi petugas kesehatan dan pasien dalam konteks budaya Asia Tenggara. Jakarta: EGC. 2017.

About the author

Ahmad Fuady was born on April 7, 1986, in Jakarta, Indonesia. Graduated from Al-Bayan Islamic Boarding School (*Pesantren*), Sukabumi, West Java, in 2003, he continued his study in the Faculty of Medicine, Universitas Indonesia, Jakarta. In 2009, he obtained his medical doctor degree. Instead of following his degree to become a medical specialist, he decided to pursue his interest in the health system to improve Indonesian population health through academic work. He joined as a junior faculty member in the Department of Community Medicine, Faculty of Medicine, Universitas Indonesia in 2010.

In 2012, he continued his study in health economics, policy, and law in Erasmus University Rotterdam, The Netherlands. After graduated from this master's program in 2013, he came back to Indonesia when his country was preparing its national health insurance through Jaminan Kesehatan Nasional to attain universal health coverage. He was involved in some economic evaluation studies and program evaluation and had started to write health policy articles in Indonesian national newspapers. His Master's thesis, 'Moving towards universal health coverage in Indonesia: where is the position?' was published as a reference book in Bahasa Indonesia, 'Jaminan Kesehatan Universal dan Pemenuhan Hak Kesehatan'. During this period, he was awarded the Young Scientist Award by the Faculty of Medicine, Universitas Indonesia in 2015.

In April 2016, he started the Ph.D. program at the Department of Public Health, Erasmus MC, University Medical Center Rotterdam, The Netherlands, focusing on the socioeconomic impact of tuberculosis in Indonesia. He is still active in producing opinion articles in national newspapers and writing books. During his Ph.D. program, he wrote a book chapter on patient-doctor communication focusing on tuberculosis and a reference book about Indonesian national health coverage – both in Bahasa Indonesia.

Acknowledgement

When I almost graduated from my postgraduate degree in health economics, policy, and law in 2013, I sent an email to a professor who then invited me to his room to present my idea. He listened to me carefully and granted me an acceptance to supervise, teach, and guide me on this journey. He is Prof. Jan Hendrik Richardus, who patiently issued my requests several times to defer the starting date of my Ph.D. program because of the lengthy, uncertain scholarship procedure. Thank you for your guidance, valuable advice, and inspiration during this journey.

Next to Jan Hendrik, there is always Tanja A.J. Houweling, who has guided me in detail. Her comments have always been constructive, valuable, and encouraging. Tanja is not only a good, strong co-supervisor. She is also my family friend, who has offered bits of help to my wife and my children. It is fantastic to know that Tanja also has Indonesian background – had researched in Jakarta, had learned Bahasa in Salatiga, speaks Bahasa well, and has a good relationship with my teachers (Firman Lubis, Joedo Prihartono, and Setyawati Budiningsih). Thank you for all your very kind support through this Ph.D. program.

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Purwito, Dewi Friska, Listya Tresnanti, Grace Wangge, Nora Sutarina, Ade Tobing, Levina Chandra, Nuril Haya, Rodri Tanoto, and all my colleagues in the department including administration staffs (Ade, Supriyanto, Deni, Nuzulia, Yanti, Fahyuni). To my Deans: Prof. Ratna Sitompul and Prof. Ari Fahrial. To my supporters: Prof. Hasbullah Thabrany, Diah Handayani, Emie Suhermi, and all my surveyor teams and my students who had involved a lot in my studies.

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My steps to Rotterdam would not start without a very long, continuous, uninterrupted prayers from my beloved parents. I am nothing without them who pour out their perpetual affection since my birth to this second. My dear Ayah: (alm) Hasuki Nasir – my patron, my teacher, with his endless patience to me. My beloved Mami: Ikrimah Rahmatullah Shiddiq – my sunshine, my light, my door opener, my home with all her prayers to Allah. Nothing can repay your love. May Allah reward you with the best thing in your life and hereafter. Also, to my family: all my big brothers and big sisters. Bung Itqon, Ka Tsauroh, Ka Yatmi, Ka Rif’ah, Ka Syafaah, Ka Irfan, Ka Nurfadhilah, Ka Ahmad Fadhil, and Ka Akmal. They have taken care of me – the youngest member in big 10 – from my little, naughty boy to this adulthood. To my brothers and sisters-in-law and my nieces.

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All of these things, this achievement, is nothing but to Allah – the purpose of my life, the side I will return. To Muhammad, peace be upon him and messenger – my very first human idol, the best model to imitate.

PhD Portofolio

Sum of registered credits (EC): 35,00

Starting date	Name	EC
Courses		
30-10-2019	Post-graduate course - An introduction to TB modelling'	0.30
15-10-2019	Health Financing for Universal Health Coverage	1.50
11-10-2019	Tuberculosis - Advanced Concepts	1.00
04-10-2019	Webinar: Assessing country progress in Health Financing: a qualitative approach	0.20
25-04-2019	Webinar: China's changing health care	0.20
18-04-2018	Webinar: Understanding Peer Review	0.20
03-11-2017	Erasmus MC - Biomedical English Writing and Communication	3.00
06-07-2017	Erasmus MC - PhD Introduction session	0.20
15-12-2016	Erasmus MC - Scientific Integrity	0.30
04-04-2016	Department - Research meetings	5.00
06-04-2016	Infectious Diseases Section - Research meetings	2.40
Conferences		
31-10-2019	International Conference, The 50th Union World Conference on Lung Health	1.00
31-10-2019	SPARKS Network, TB Social Protection Meeting	0.20
13-06-2019	RGHI Network Meeting, Social Protection in Health	0.20
24-10-2018	International Conference, The 49th Union World Conference on Lung Health	1.00
23-10-2018	International Conference, TB Science 2018	0.80
22-02-2018	RGHI Network Meering, Patient costs	0.20
14-08-2017	International Conference - The 2nd International Conference on Global health 2017	1.00
11-05-2017	Regional conference, lolaHESG 2017	0.80
29-03-2017	Research Meeting, The 42nd Tuberculosis Surveillance and Research Unit Meeting	1.00
22-03-2017	International Conference, The 6th Conference of The Union Asia Pacific Region	1.00
Oral and poster presentations		
31-10-2019	Poster presentation, The 50th Union World Conference on Lung Health, Hyderabad, India	1.00
31-10-2019	Oral presentation, The 50th Union World Conference on Lung Health, Hyderabad, India	1.00
24-10-2018	Oral presentation, The 49th Union World Conference on Lung Health, The Hague, The Netherlands	1.00
22-02-2018	Oral presentation, Rotterdam Global Health Initiative, Rotterdam, The Netherlands	1.00
14-08-2017	Speaker - The 2nd International Conference on Global health 2017, Jakarta, Indonesia	1.00
11-05-2017	Oral presentation, lolaHESG 2017, Rotterdam, The Netherlands	1.00
29-03-2017	Oral presentation, The 42nd Tuberculosis Surveillance and Research Unit Meeting, Johannesburg, South Africa	1.00

Starting date	Name	EC
22-03-2017	Oral presentation, The 6th Conference of The Union Asia Pacific Region, Tokyo, Japan	1.00
Peer reviews		
06-11-2019	Peer review, IJTLD	0.30
30-09-2019	Peer Review, The Royal Society of Tropical Medicine and Hygiene	0.30
03-06-2019	Peer review, BMJ Open	0.30
13-05-2019	Peer review, The Royal Society of Tropical Medicine and Hygiene	0.30
02-03-2019	Peer review, Medical Journal of Indonesia	0.30
22-02-2019	Peer review, The Royal Society of Tropical Medicine and Hygiene	0.30
28-01-2019	Peer review, BMC Public Health	0.30
25-01-2019	Peer review, BMJ Open	0.30
18-09-2018	Peer review, Plos ONE	0.30
04-09-2018	Peer review, Medical Journal of Indonesia	0.30
06-08-2018	Peer review, Medical Journal of Indonesia	0.30
Teaching		
08-08-2017	Indonesian Health Financing System, teaching for undergraduate medical students of Faculty of Medicine, Universitas Indonesia	1.00
07-08-2019	Indonesian Health Financing System, teaching for undergraduate medical students of Faculty of Medicine, Universitas Indonesia	1.00
25-06-2019	Preparation class for medical student in the Global Health course, posted in Indonesia	0.20