The Missing Link:
Unravelling Household Welfare Dynamics in Tuberculosis-Affected Families – a West Java Case Study

A Research Paper presented by:

Salma Nur Annisa
(Indonesia)

in partial fulfilment of the requirements for obtaining the degree of
MASTER OF ARTS IN DEVELOPMENT STUDIES

Major:

SPD
Social Policy for Development

Members of the Examining Committee:

Dr. Gerard McCarthy
Dr. Karin Astrid Siegmann

The Hague, The Netherlands
December 2023

Table of Contents

List of Figure

List of Tables

List of Appendices

List of Acronyms

BFP	*Bolsa Familia Programme*
BPNT	*Bantuan Pangan Non-Tunai* / Non-Cash Food Assistance
CBO	Community Based Organizations
CCT	Conditional Cash Transfer
COVID-19	Coronavirus disease 2019
DOT	Directly Observed Treatment
DR-TB	Drug-Resistant Tuberculosis
DS-TB	Drug-Sensitive/Susceptible Tuberculosis
FAO	Food and Agriculture Organization
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
ISS	Institute of Social Studies
JKN	*Jaminan Kesehatan Nasional* / National Health Insurance
MDR-TB	Multidrug-Resistant Tuberculosis
Mtb	Mycobacterium tuberculosis
NTP	National Tuberculosis Programme
PICOT	Patient, Intervention, Comparison, Outcome, Time
PMDT	Programmatic Management of Drug-Resistant Tuberculosis
PMO	*Petugas Minum Obat* / Medicine Supervisor Officer
Puskesmas	*Pusat Kesehatan Masyarakat* / Community-Based Health Centers
SPM	Social Policy Measures
TB	Tuberculosis
WHO	World Health Organization

Acknowledgements

First and foremost, I want to sincerely thank each and every one of my informants for giving of their time and sharing of information with me. This study would not have been possible without them. In a short period of time, they have shown me unwavering warmth and kindness in addition to helping me with my academic endeavours. They are my main sources of inspiration when I encounter challenges along the way.

I would also like to express my gratitude for Dr. Gerard McCarthy, my supervisor, for always challenging me academically and introducing me to a variety of novel perspectives. His patience and guidance helped me to complete this study from start to finish. And to my second reader Dr. Karin Astrid Siegmann for her insightful feedback which helped me discover how much I appreciate the gendered approach to health issues, something that I would very much like to pursue in the future.

Thanks to my family—Ridwan, Heni, Runi, and Minerva—who supported me throughout my master's degree even before I started. To all of my friends on ISS especially PPI KDH 23 (Sisil, Haliza, Ismi, Ivy, Ela, Wulan, Dedy, Akita, Rigine, Vita, Indi, Azka, and Izu) and back in Indonesia (Kiki, Anton, Livia, Nissa, and Atha) who have provided with persistent moral support. To Mo and Luke, who supported me during the most trying time of this adventure. And all of the SPD faculty members who had helped me out financially with my fieldwork. Their unyielding support has been an incredible blessing.

I am also immensely thankful for my dear mentors and research partners, dr. Bony and Mbak Manda, for welcoming me into their world and consistently fostering hope and inspiration within me.

Finally, I want to extend my heartfelt appreciation to Dennis Jansen for always being delightfully silly, a source of comfort that help me stay grounded.

Abstract

The objective of this study is to investigate the welfare dynamics of households affected by tuberculosis in West Java, Indonesia. Since the inception of the WHO's End TB era in 2015, there has been a growing body of evidence concerning social protection for tuberculosis. However, most of these initiatives have been heavily state-centric, focusing on short-term risk mitigation for single individuals in hoping for improving adherence, and thus exempting families in the process. On this account, given the absence of formal state protection and the high reliance on family and community support in Indonesia, it has become imperative to also consider the impact of TB from a family perspective.

To address this gap, this study adopts an informal social protection framework to map out the various actors and their roles within the TB welfare ecosystem. Additionally, the study investigates the most commonly used coping strategies by families and explores the potential implications of these strategies. From the fieldwork it reveals that three major actors are involved in providing welfare for TB patients: the family (immediate and extended), the community (*Puskesmas* and CBO), and the state (through the family). Among these actors, the family serves as the primary safety net for most TB patients. Moreover, the coping strategy frequently employed involves kinship claims through intra-household labour substitution. A deeper look into this particular strategy reveals TB renders a significant shift in the division of labour within households, with women often taking on the role of shock absorber.

Relevance to Development Studies

Tuberculosis as quotes by Smith, Herington and Loshak (2021) is a "social disease with medical dimension" in which the underlying causes are social inequalities and social determinant of health. In his 1997 essay entitled "Social Scientist and the New Tuberculosis," the late Paul Farmer advocated for a more social approach to tuberculosis in order to identify societal dynamics that could perpetuate socioeconomic injustices and poor health, and ultimately prolonged transmission or re-emergence of TB. This study is to answer the call through identifying potential household-level social forces, and how these forces may render implications towards TB-affected households.

Keywords

Tuberculosis, family, household, disease burden, informal social protection, social policy

1. Tuberculosis: The Situation Today

Tuberculosis (TB) is an infectious disease caused by Mycobacterium tuberculosis (Mtb). It typically affects the lungs, but it can also affect other organ systems other than the lungs. Drug-sensitive tuberculosis (DS-TB) is the most prevalent form of tuberculosis. It's a form of tuberculosis that is treatable with standard anti-TB medications. When TB patients don't complete their course of treatment or take the incorrect dosage of drugs, Mtb strains can become resistant to at least one of the most powerful anti-TB drugs, rifampicin, and isoniazid; this condition is known as Drug Resistant TB (DR-TB). When a person develops resistance to both first-line drugs (rifampicin and isoniazid), they have multidrug-resistant tuberculosis (MDR-TB). Because the treatment is longer and more toxic to the patient, the DR-TB treatment regimen with second-line drugs is prone to treatment drop out and has a higher rate of failure and mortality rate, and it carries a much higher socioeconomic burden for both the patients and their families (Emerson, Fretz and Shaw, 2011). The standard duration of treatment for DS-TB typically ranges from 6 to 12 months, whereas for DR-TB, the treatment duration can extend up to 20 to 30 months for completion.

In 2022 alone there was an estimated of 10.6 million people contracted with TB and a total of 1.3 million died (WHO, 2023). Globally, TB is the second leading infectious killer before COVID-19. Indonesia is the second country with the highest TB burden, according to the 2022 annual Indonesia TB control report, estimated incidents increased significantly from 824,000 in 2020 to 969,000 in 2021 due to a decrease in case findings (Ministry of Health, 2022). These trends indicate that fewer TB cases were identified and treated, could result in an increase in TB mortality, community transmission, a rise in DR-TB cases, and an overall prolonged disease pandemic.

Despite the fact that effective tuberculosis is preventable and treatable, it remains a major public health threat, particularly in the global south. The majority of TB cases are evidently occurring in low and middle-income countries, and the poor have always been disproportionately affected. Poverty and TB have always been inextricably linked. Individuals who are poor are at a higher risk of contracting TB due to precarious living conditions (e.g., poor housing, long working hours, malnutrition) (Moreira, Kritski and Carvalho, 2020). At the same time, people with TB, particularly the poor, may find themselves spiralling into ever deeper poverty, alongside worsened quality of life due to gradual

welfare losses caused by the high medical or non-medical cost associated with TB, as well as social stigma, which may have caused them to be excluded from present and future support. While TB treatment and drugs are free in many global south countries, coverage is still mostly limited to diagnostic tests and drugs, leaving patients and their families to bear hidden costs such as food, transportation, hospitalization, and opportunity costs among other costs (Wingfield *et al.,* 2016).

1.1 Tuberculosis and Household

It's well-established that TB places a substantial financial burden on individuals, primarily because the side effects of treatment often render patients unable to work, especially during the intensive phase. This phase lasts 1-2 months for DS-TB patients and 8-12 months for DR-TB patients. Many studies on disease burden and consequences tend to focus primarily on the burden borne by a single patient: for example, how loss of income may impair treatment adherence. Resultantly, recommended policy interventions are frequently tailored to address problems that appear on an individual basis. The most common method for assessing the TB burden is to calculate household health spending. A household's situation is classified as catastrophic if they spend more than 20% of their out-of-pocket expenses on TB medical care and indirect costs (such as income loss, transportation, and food). This rationale is frequently used as a basis in many studies to identify components that may contribute to the catastrophic cost; or how the cost correlates with care-seeking behaviour. Up to now, although there has been recognition that the burden also impacts the family through "household expenditure," little attention has been given to understanding precisely how this cost affects the family—the institution that, more often than not, bears both the cost and the consequences.

A better understanding of such issues is especially important in countries like Indonesia, where TB patients rely heavily on informal social protection arrangements provided by family and community. This dynamic indicates that if even one family member falls ill the burden can influence the whole family's welfare, considering that family as it stands is an institution built on shared duties and resources. The impact of health shocks on families can have several implications. For instance, in the event that the primary provider or breadwinner becomes infected, there arises a question of who would assume the responsibilities typically performed by the provider. How might a family adapt to a sudden loss of income? Are there any additional actors who may be involved in

the provision of welfare to the affected family? Examining these questions could allow us to unveil hidden features that cannot be captured by individualistic measurement. Hence, it's imperative to learn about this intricate dynamic to gain a more holistic understanding of the impact of TB.

1.2 Research Question and Objective

1.2.1 Research objective

The primary objective of this study is to investigate the livelihood dynamics of households impacted by TB. This involves examining how families cope with sudden health shocks, and the subsequent consequences of the coping mechanism. Moreover, the aim of this study is also to map out the welfare ecosystem by identifying potential actors beyond the immediate/extended family who may contribute to the welfare support of the patient or household. Additionally, this study will also try to examine the mechanisms employed by these actors in distributing assistance to the affected families. In short, the objectives of this study are:

1. To understand the welfare dynamic within the family
2. To identify household coping response towards health shocks
3. To identify actors and their roles within the TB welfare ecosystem

1.2.2 Research questions

How does the livelihood dynamics within a family change due to TB, and in what ways do these dynamics influence the family's livelihood?

Sub-questions:

1. To what extent TB burdens influence household livelihood?
2. What are the burdens and challenges faced by family and patient?
3. What are challenges faced by the community in providing support to family and patient?

2. Conceptualizing Social Protection for TB

2.1 The Current State of TB Social Protection

Within the past decade there has been a growing demand for social policy interventions that extend beyond universal healthcare. Such interventions are commonly dubbed as "social protection for TB" and have been a recurring topic of discussion in the broader discourse on social determinants of health. However, it was not until the implementation of the World Health Organization's (WHO) End TB Strategy in 2015 that the importance of social protection in global TB efforts gained significant attention. Consequently, there has been a more serious consideration of socioeconomic measures in the discourse surrounding TB.

The WHO's strategy for social protection for TB places strong emphasis on the need to reduce catastrophic costs associated with TB. In both the 2015 and the most recent 2020 updates to this strategy, the WHO establishes a standardised principle for assessing the economic hardships imposed on households due to TB. The principle asserts that the primary unit of measurement in the evaluation of TB burden is a combination of both direct and indirect costs which comprise of: (1) out-of-pocket payment for TB diagnosis and treatment; (2) expenses related to the use of TB health services; and (3) income loss. The intent of this measurement is to identify the factors that may contribute to the catastrophic cost, enabling countries to better assess the level of financial protection provided to households. This, in turn, could help reduce barriers to treatment adherence (WHO, 2015)

While WHO refrains from endorsing a definite policy when addressing particular issues and recognizes the need for a more adaptable approach, the 2015 End TB strategy and the 2022 sequential update have clearly outlined the principles of social protection for TB, that is: interventions aimed at addressing downstream outcomes, such as improving health outcomes and preventing ongoing impoverishment resulting from patient costs, are to be prioritised in order to disrupt the course of TB epidemic.

Such notions, which have a clear state-centric bias and a preference for financial remedies, clearly influence the growing body of research on social protection related to TB Todd *et al.,* (2023) scoping review of Social Protection Measures (SPM) for TB-affected households provides an overview of the current state of SPM for TB. The study includes 49 articles (38 academic articles

and 11 grey literatures from various international organizations). There were 43 social protection programmes and interventions identified, which were further classified into three distinct categories: financial intervention, food assistance, and community participation. Half of the interventions were TB-specific, aimed specifically at individual with TB. The eligibility criteria for the interventions were based on poverty, malnutrition, and assessment by social worker or health care worker. The majority of the programmes and interventions are financial in nature, primarily in the form of conditional cash transfers (CCT), with nonfinancial support measures accounting for less than 10%. The figure is not surprising given that: (1) conditional/unconditional cash transfer programmes or other financial incentives are the most common SPM globally; (2) financial incentive, particularly cash transfer, has become an integral part of other disease response such as HIV/AIDS; and (3) monetary incentives have been shown to have favourable effects, particularly on human capital dimensions such as health (Lagarde *et al.*, 2009; Pettifor *et al.*, 2012).

Andrade et al. (2018) conducted a systematic review and meta-analysis of studies between 1995 and 2016 in low and middle-income countries. They explored the impact of social policy on TB outcomes, including financial interventions (e.g., cash transfer) and non-financial interventions (e.g., counselling, socio-educational approaches, community support). Their findings showed a positive association between social policy and improved TB outcomes, particularly reduced risks of treatment default and therapeutic failure. Notably, the most significant improvements were observed when non-financial interventions or a combination of financial and social support were implemented.

While there is no consensus regarding approach for the implementation of social protection for TB, recent studies conducted by Todd *et al.,* (2023) and Andrade *et al.*, (2018) have revealed that financial interventions, which aim to facilitate improved treatment adherence and enhance therapeutic outcomes, play a fundamental role in the execution of many TB social protection programs. It's worth mentioning that there are also TB-specific social protection programs aim to address not only behavioural change but also the broader effects of poverty, such as food insecurity. The *Bolsa Familia Programme* (BFP) in Brazil is an example of this strategy.[1]

[1] *Bolsa Familia Programme* (BFP) in Brazil provides income assistance cash transfers to impoverished households that participate in pro-health and education activities. (Oliosi *et al.,* 2019) reveals that individuals who were exposed to the (conditional) cash transfer scheme had a higher chance of positive therapeutic outcome

This social protection adheres to the traditional social protection framework, which can be described as formal interventions, typically in the form of government programme, aimed at mitigating inequalities. These initiatives typically focus on bolstering human capital and financial resilience, especially among vulnerable populations (World Bank, 2023; European Parliament, 2013). The overarching objective of formal social protection is to empower individuals, facilitating their transition into productive, contributing members of society. In the context of TB, this intervention serves as a temporary safety net, preventing individuals from plunging further into poverty and equipping them for a return to the labour market once they are recovered.

Taking this into account, I believe that this state-centric, economically oriented model of social protection for TB has yielded a static perspective on TB burden. This often leads us to assume that the burden only occurs at the individual level, and the sole solution is through financial remedies. Andrade *et al.,* (2018) highlighted the presence of other forms of protection and the involvement of non-state institutions in TB social protection but then again, they primarily focused on patients' care seeking behaviour. In order to have a better understanding of the multifaceted burden posed by TB, I argue that it's crucial we look at the household level and uncover how the proclaimed burdens impact families and how they cope with such stress.

2.2 Produtivist Bias: The Cost of Illness and Human Capital

Before delving into an alternative concept of social protection, it's essential to first briefly discuss how the WHO approaches TB-related social policy. WHO's version of social protection for TB is significantly shaped by the cost of illness technique in which the financial burden of disease is measured through two main categories: direct costs and indirect costs.

The term indirect cost encompasses costs associated with both the diagnosis and treatment of a medical condition, as well as non-medical costs like transportation or nutritional support (Rice, Dorothy P., 2000; Liu *et al.,* 2020; Rice, D. P., Hodgson and Kopstein, 1985). In contrast, indirect costs refer to expenses that are not directly related to healthcare but instead capture the wider economic consequences of a disease. Indirect cost is typically quantified by measuring the reduction in productivity resulting from either mortality or morbidity (Rice, Dorothy P., 2000; Rice, D. P., Hodgson and Kopstein, 1985).

The cost of illness approach is conceptually grounded in human capital theory, which conceptualizes individuals as workers that generate a continuous

flow of production over time, with output value attributed to their income (Basakha *et al.,* 2021). In short, the valuation of one's life is predicated on the individual's participation in the labour force and their market earnings. Consequently, the cost of illness involves calculating these output losses resulting from disease or injury.

The perception that the burden is solely carried by the patient through their productive output (earnings) is analytically constraining. A tendency to individualise monetary outcomes leads to a disregard for factors beyond the individual that also substantively determine successful recover such: the availability of additional resources, strategies and support from family, all of which play a critical role in how the individual copes with the health, financial and social shock associated with TB.

2.3 Informal Social Protection

Before defining what is informal social protection, I think it's also important to establish the notion of social capital which is one of the structures of informal social protection. According to (Portes, 1998) social capital refers to an individual's capacity to obtain advantages through their connections with social networks or social structures (p. 6). such as family support, which allows individuals to access the emotional and financial resources of their family, extra-familial networks, which are resources sourced from outside the household, and social norms, which are derived from a sense of obligations arising from internalized dominant social norms within a given society.

With that in mind we need to acknowledge that most global south countries, which bear the brunt of the TB burden, cannot simply conjure the social protection measures proposed by the WHO due to various challenges ranging from limited resources to institutional capacity. Consequently, welfare for patient usually coming from networks of family and friends, or other institutions. Examining social policy discourse may offer an alternative perspective through which we can explore these alternative forms of social protection for the context of TB. Apart from the state, there are also non-state actors who also play a crucial role in providing welfare ranging from social networks such as family and friends, neighbourhoods, religious institutions, and non-government organizations.

The involvement of these non-state actors in social welfare becomes more pronounced within an informal security welfare regime, one of the three typologies of welfare regimes developed by Wood and Gough (Wood and Gough, 2006).

This particular regime is characterized by low government responsibility, the presence of extensive personal networks and social capital, as well as an expansive role for private markets and community-based organizations (Wood and Gough, 2006; Gough, 2004). In situations where the state falls short in providing public provision (health care, education, employment etc.,) to its citizens, various other institutions may step in to fill the vacuum left by the absence of state role. Existing scholarship conceptualises these actors as providing informal social protection.

In examining variety of definition of informal protection, (Mumtaz, 2022) defines informal social protection as:

> "The set of informal private interventions by the family (extended and immediate), religious organizations, NGOs (local and international) and neighbourhood, friends, and village communities aimed not only for supporting the poor and more vulnerable members of the family for meeting their basic needs but also helping them to improve their risk administration and assisting them towards building their human capital by acquiring skill or technical training." (p. 5)

He then classifies the primary providers of informal social protection and the components that govern how assistance is regulated. The three main providers encompass family (immediate and extended), religious organizations, and non-governmental organizations (NGOs). The components of informal social protection include informal assistance (e.g., cash or in-kind aid), insurance (i.e., contributory and non-contributory risk management), and labour market measures (i.e., human capital development).

While Mumtaz (2022) lay out the institutions and the components, Razavi (2007) care diamond offers valuable insights into how various actors interact and influence the development of welfare regimes from the perspective of the care economy. This framework helps conceptualize the interplay between different societal institutions, including the market, state, family, and non-profit organizations, in the provision of care. These institutional arrangements can be dynamic and adapt to changes in social and political contexts, especially in developing societies (Peng, 2019; Razavi, 2007). She provided a compelling example of the increasing demand for greater public responsibility in providing care for HIV/AIDS patients in some Southern African countries. This demand arises because women, primarily responsible for caregiving, are disproportionately affected in term of care burden. In response to this, some of the state start exploring alternatives like home-based care, which complements the usually

unpaid family care, it also serves as a substitute of inpatient care amidst limited health care capacity. Most home-based caregivers operate voluntarily and may even contribute their own resources to support the households they assist.

In the context of chronic disease in developing countries, informal social protection plays a great role in providing livelihood support particularly in the level of family institution but rarely get its due attention due to the tendency of treating disease as an individual rather than household and communal problem.

2.3.1 Informal social protection in health

In assessing disease burden Sauerborn, Adams and Hien (1996) and Russell (1996) highlighted importance of examining the burden of illness and coping mechanism at a household level. Their study suggests that even with only one ill person in the family the cost largely occurred at the level of households, with family-members employing different coping strategies depending on financial and social resources at hand. Both studies in particular spotlighted the critical role of kinship-claims.

As Russell (1996) highlights, when facing sudden health contingency poor households are also faced with the challenge of managing a constrained budget alongside other household obligations, necessitating careful prioritization of household expenditure. These resource allocation tactics come with their own associated costs and trade-offs. For instance, intra-household claims for medical emergency may create tensions within the family, while reducing healthcare expenditure for other needs poses risks to overall health and well-being of the ill family member.

Drawing upon the insights of Russell (1996), Goudge *et al.,* (2009) conducted a study in South Africa to investigate what it means for poor families to rely on informal social protection in the face of chronic illness in the household. They found that in resource-poor settings there is extreme dependence of patients on social resources, including intra-household transfers of financial resources and time, as well as community support in coping with health shocks. And while social resources do offer some relief in mitigating the adverse financial impacts of chronic illness, the research also illuminates the limits of this resilience, with family-level chronic illness often gradually eroding household livelihood.

Both Russell (1996) and Goudge *et al*., (2009) highlight the insufficiency of relying solely on social resources to ward off financial distress. The study emphasizes the critical importance of both formal and informal social protection

mechanisms in resource-limited settings. This is further substantiated by the findings that families benefiting from both formal statutory and informal social protections exhibited enhanced resilience in coping with the financial pressures stemming from chronic illness.

Nevertheless, their research exposes how social resources and family coping abilities are often framed simplistically in research on chronic illness as sources of patient resilience. Contrary to this approach, however, their findings reveal that poor households often engage in an exchange of livelihoods, which ultimately exposes them to greater vulnerability in one way or another.

2.4 Conclusion

By using Mumtaz (2021) conceptualization of informal social protection it would allow us to explore the impact and burden of TB from a family level. The significance of using household as a unit of analysis is because studies by Studies by Russell (1996), Sauerborn, Adams and Hien (1996), and Goudge *et al.*, (2009) demonstrate that ill individual mostly relies on their social networks, particularly families, in securing their livelihood. Consequently, the disease burden's trickle-down effect will also impact families. In short, because families and individuals are interconnected, the welfare of the entire family may be compromised when even only one member becomes ill. This matter calls for a need to move beyond a rigid productivist focus on the cost of illness for the individual.

3. Methodology

3.1 Design and Approach

This study primarily uses qualitative methods and draws from the insights of various people affected by TB. The reason for opting for qualitative methods, rather than the more numbers-focused quantitative approach often used in health research, is to simply offer a conversation based upon experiences of those affected by TB. The open-ended nature of qualitative approach will allow the study to unravel the answer not based on the researcher's assumption but from the frame of reference of the participants (Bogdan and Biklen, 1998). Therefore, this study hopes to complement the existing body of research, which predominantly focuses on the system and structure in which these individuals are embedded.

The strategy that is used for data collection is semi-structured in-depth interview to elicit individuals' life histories, lived experiences, perceptions, and views (Renjith *et al.,* 2021). Before commencing the fieldwork, three sets of predetermined open-ended questions were developed. These question sets were tailored for three distinct groups of participants: patients and their families, healthcare workers, and CBO (community-based organization) personnel. The questions for patients and their families aim to delve into their experiences, available support networks, and coping strategies. Meanwhile, questions for healthcare workers and CBO personnel sought to understand their role in supporting patients, whether through medical aid or other social assistance and how they negotiate with the limitations of the system to aid patients and their families.

A non-probability purposive sampling approach is employed to specifically select potential participants. The aim of this sampling method is not to establish a representation of a larger population but to include individuals who have actively engaged in the system related to the study's subject (Tansey, 2007). One of the primary critiques of this sampling method is its susceptibility to biases (both in selection and motivation) due to the highly subjective nature of the approach.

This long-standing sampling parable is briefly discussed by Tansey (2007) in her discussion of elite tracing and sampling methods. She contends that when the goal is not generalization but rather the collection of insights from individuals intimately engaged in the process of interest, non-probability sampling can serve as a valuable approach. The use of probability sampling, in contrast, may

constrain this type of explorative study. Non-probability sampling in purposeful form permits the population to be customized in alignment with the study's precise objectives, ensuring that the selected participants are the most informative. Moreover, it aids in capturing the nuances that might be difficult to capture through probability-based sampling methods.

With this in mind, the primary goal of this study is not to generalize the various beliefs or actions within the subset population chosen. Instead, it aspires to explore and engage the experiences lived by the population, with the hope of shedding new light on how TB impacts patients, households, healthcare workers, and civil society staff, given the multifaceted nature of TB.

3.2 Study Sites and Informants

Additionally, in an effort to complement the existing research on the impact of TB on livelihood in Indonesia this study adapts inclusion criteria based on the populations selected in prior studies, with a slight modification to include relevant criteria for this study. These criteria include TB patients or former patients (those who have successfully completed treatment), adult patients, and individuals who resided with their families during the treatment period.

As West Java serves as the case study, the sites where the majority of participants, particularly patients and former patients, were "recruited" are situated in two Puskesmas[2], one located in Bandung city and the other in West Bandung Regency. The initial plan to conduct the study in two distinct settings, namely urban/city and rural/regency, is driven by the aim to explore potential variations in experiences among patients from urban and rural environments. This decision is motivated by previous studies that has identified differences in healthcare-seeking behaviour, TB care accessibility, as well as stigma and discrimination between rural and urban settings (Rintiswati *et al.,* 2009; Fuady, Houweling *et al.,* 2018a; Mahendradhata, Syahrizal and Utarini, 2008).

Puskesmas, serves as the central hub for participant 'recruitment' and interviews. There are two primary reasons behind this choice. First, a significant majority of TB cases at the sub-district level are managed by Puskesmas, making

[2] Puskesmas is a government-mandated community health centre, responsible for delivering primary care at the sub-district level. Puskesmas is primarily funded by the central government, regional/provincial governments, and district governments through the Health Operational Assistance (*Badan Operasional Kesehatan*/ BOK) program. Furthermore, Puskesmas is eligible for capitation funds from the Social Security Agency for Health (*Badan Penyelenggara Jaminan Sosial*/BPJS). The Capitation Fund is the amount of monthly payment made in advance to primary health care facilities depending on the number of registered participants, regardless of the type or quantity of health services provided.

it the primary point of contact for my informants, who are TB patients. More details about the system will be discussed in the next section. Essentially, Puskesmas was the gatekeeper to the majority of the individuals I eventually interviewed.

Second, my decision was influenced by challenges I encountered in trying to reach patients through a snowballing approach, before gaining access to the Puskesmas. Initially, I attempted to connect with several patients through personal contacts, which led to interviews with former TB patients in Tasikmalaya regency, and mothers of TB-affected children. Nevertheless, while this approach yielded some valuable insights, my attempt to reach out to the Indonesia TB online community through Facebook was not successful. This ultimately pushed me to choose Puskesmas as the focal point of my study.

Table 1 Informant Profiles

No	Pseudonym[3]	Status	Occupations	Date of interview
1	Yayan	Former patient	Housewife	19 July
2	Tuti	Former patient	Housewife	19 July
3	Sita	Former patient	Housewife	19 July
4	Kura	Former MDR-TB	CBO staff (previously housewife during treatment)	5 August
5	Tita	Former MDR-TB	CBO staff	5 August
6	Hari	Former patient	Small business	7 August
7	Emas	Pulmonary TB	Housewife	31 July
8	Ahmad	Pulmonary TB	Farmer	31 July
9	Saep	Pulmonary TB	Construction worker	3 August
10	Didi + Talimah (daughter)	Pulmonary TB	Contractor	3 August
11	Kurnia + Siti (wife)	Pulmonary TB	Manufacture	4 August
12	Fahri	Pulmonary-TB	Online driver	7 August
13	Amin + Fatimah (sister)	Pulmonary-TB + BPNT receiver	Construction worker	7 August

[3] The name used on this research paper is a pseudonym rather than the informant's true name. In order to protect the informant's privacy, this was done at their request.

14	Silvia	Nurse	Nurse	7 August
15	Devi	Nurse	Nurse	12 August
16	Desi	Head of CBO	CBO staff	18 July
17	Kura	Patient support	CBO staff	6 August
18	Tati	Patient support	CBO staff	6 August
19	Rizki	Family member + BPNT receiver	Small business (previously housewife)	19 July
20	Ismi	Family member	Housewife	2 August
21	Fadimah	Family member + BPNT receiver	Small business (previously housewife)	31 July

3.3 Limitations

The decision to choose Puskesmas as my focal point, while efficient, comes with certain implications. Since I only interviewed patients from the Puskesmas, and only one former patient had used a private provider, this study won't be able to provide a comprehensive perspective on individuals who seek care from other non-public providers, such as private facilities or alternative medicine.

Multiple studies have highlighted differences in the socio-economic burden faced by patients seeking treatment at Puskesmas versus private providers (Hafez, Harimurti and Martin-Hughes, 2020; Fuady *et al.,* 2020a; Fuady, Houweling *et al.,* 2018b; McAllister *et al.,* 2020a). Patients who opt for private providers typically incur higher costs and are more vulnerable to health-related financial shocks, both prior to and during treatment. As a result, this study may offer limited insights into the experiences of this particular group. Additionally, this research might not be able to fully address issues related to stigma and discrimination, as individuals facing significant stigma may choose to avoid visiting the Puskesmas entirely.

3.3 Reflexivity

Having expressed concerns about the internal and external validity related to the qualitative method I'm employing, it's important to discuss how I plan to address these issues and ensure the integrity of my study: What parameters will I use for quality control?

Like many other qualitative studies, one approach to enhance the credibility of my study is by acknowledging my own subjectivity. As (Behar, 1997)

emphasized, the researcher's subjectivity should be transparent and open to critical scrutiny by the readers because the researcher acts as the instrument, thus their beliefs and behaviours are integral components of empirical evidence— they ultimately shape the entirety of the study process. And thus, to begin, I will address my positionality, perception, and how these influence my study process and particularly the power relations between me and my participants during the fieldwork.

Long before my academic engagement with TB, my first experience with it was actually when three of my closest family members: my mother, my sister, and my uncle got infected with the disease. In hindsight, having this shared experience in addition to academic engagements with TB posit me as an 'insider' which giving me a head start in learning about the topic and understanding nuanced reactions of informants; it helped the researcher to more sensitized to certain language and dimension of the data (Berger, 2015).

Before this research paper I have started my personal academic journey, studying public health issues, between 2020-2022. During that time, I had my fair experience direct or indirectly engage with different stakeholders such as government officials, doctors, nurses, researcher, and NGO personnel but never patient nor their family. As such, my perception towards TB is that it's a disease of poor people; that there are issues with treatment compliance issue because despite free TB care patients are reluctant to adhere to the treatment; and that therefore we need to do something to improve patient compliance. These three perceptions ultimately shaped my study design and interpretation of my data and its implications, even after these perceptions were contested by my informants' testimonies.

While I believe that my positionality certainly influences them to be more open or vice versa, I wouldn't be so bold as to claim that it precedes their agency—their decision to choose and share that experience, to let me to take a peek into their world. They are after all people who have been within and engaging the system far longer than I do.

Furthermore, while I can consider myself as an insider in some aspect due to similarities in engaging with the system that govern TB control, I cannot say the same, at least to a degree, for other dimensions particularly concerning distress that TB subjected to most of my informants coming from the Puskesmas. While I may share a degree of experience being one of the family members infected with TB, besides the obvious reason that I was never a patient, my

middle-class privilege meant my ill family members were able to opt-out of government care and instead utilize TB care from private providers.

I acknowledge that the presence of class disparities significantly influences both my own perspective and the power dynamics between myself and my informants. I realized that due to my foreignness, which is female from a middle-class background with minimal Sundanese accent and visible frequent interactions with nurses in Puskesmas, some of my informants have exhibited hesitancy in sharing the full extent of their experiences. They perhaps perceive me as an 'extractive researcher' collecting information and then departing. Conversely, certain informants were eager to assist me in understanding their circumstances, as they perceive me, in my role as a researcher, as someone who may advocate for their issues. In the end, despite my foreignness, some participants were willing to be vulnerable and open with me, for which I am eternally grateful.

4. A Brief History of Indonesia Health System and National TB Programme

4.1 Indonesia Health System and the National TB Programme

Before delving into the discussions, it's imperative to briefly examine the evolution and operation of the National Tuberculosis Programme (NTP) and the healthcare system in Indonesia. This is vital because the effectiveness of TB control is intricately linked to the robustness of this healthcare system.

A significant change in Indonesia's healthcare system occurred in 2001 when democratic governance officially replaced the previous system of government. This shift was influenced by several factors, including the severe Asian economic crisis of 1997 and the overthrow of the authoritarian Suharto regime in 1998. During this period the country shifted from a centralized, autocratic government to a decentralized one, adopting a neoliberal economic model. This reform involved the transfer of financial, administrative, and political authority from the central government to sub-national entities like provincial and district (city and regency) governments.[4] Moreover, during this time, there was also a notable increase of public services privatization due to deregulation.

This reform had a substantial impact on the healthcare system in Indonesia. Sub-national governments, represented by provincial and district health offices, were granted the authority to adjust their health planning, financing, and healthcare services to their regional needs. As per World Bank endorsement, this system is thought to be expected to enhance the performance of the health system at the district and city levels, but its effectiveness remains a subject of scrutiny (World Bank, 2005, pp. 174-175). Furthermore, privatization has enabled a substantial expansion of privatized health services.

These changes have two significant implications for TB control, especially concerning financing and the cohesion of the public-private mix. First, health financing, including TB control, has become entirely reliant on the district budget, as the financial responsibility was shifted to sub-national governments. However, public goods like healthcare are still provided by the central government through block grants. Nevertheless, the allocation of budgets (i.e., which

[4] Regency (*kabupaten*) and city (*kota*) are at the same level of governance but typically differ in terms of the regional leadership, with the head of a regency referred to as "*bupati*," while a city is led by a "*wali kota*." They also vary in terms of their geographical size and population density. Regency generally has larger land areas and low to moderate population density, whereas cities tend to be smaller in size but have higher population density.

programs to prioritize and which ones to allocate resources to) is determined by the sub-national government (World Bank, 2005; WHO, 2009). This situation has resulted in a notable underfunding of TB control, primarily because disease control has not been a foremost concern for sub-national governments, and this predicament persists as a contemporary challenge. This concern is evident in the latest 2022 annual TB report, where funding for TB programs in Indonesia remains predominantly reliant on external donors, notably the Global Fund[5], and the central government. Contributions from sub-national governments only account for a mere 13% of the total TB funding in Indonesia, as indicated in Figure 1 (Kementerian Kesehatan Republik Indonesia, 2022). This is a cause for concern, especially when considering that localized TB programs are intricately engaged in the delivery of TB care and control.

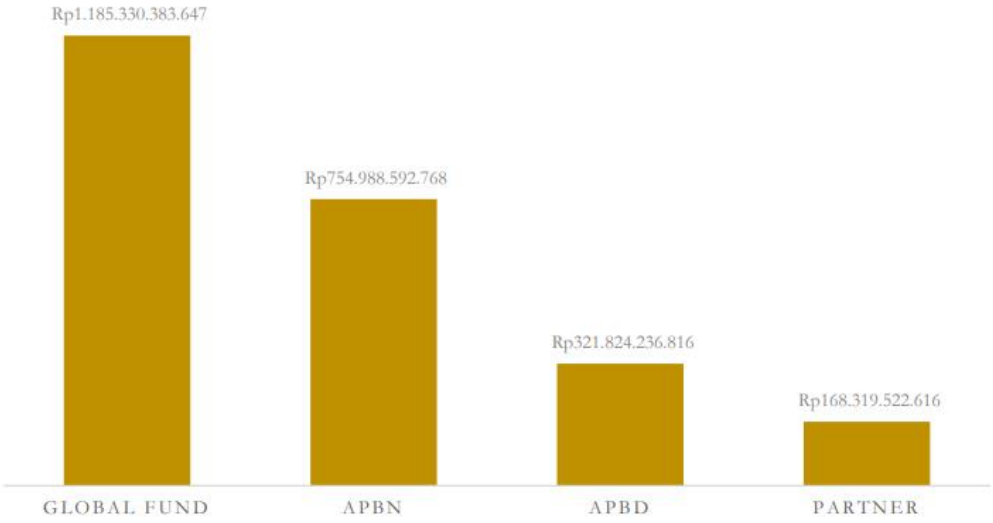

Figure 1 Indonesia TB Funding Sources 2022

Secondly, deregulation and privatization have motivated doctors to establish their private practices, leading to expansion of private clinics. This shift in healthcare services has resulted in class divisions, with wealthier and middle-class individuals preferring private healthcare provider due to the perceived better quality, while lower-income populations tend to depend on public provider such as Puskesmas (Kristiansen and Santoso, 2006; Rokx *et al.*, 2010). In the context of TB, this situation has led to fragmented TB control efforts, giving

[5] The Global Fund is an international finance agency that focuses on investment for disease control and management for three major communicable diseases: tuberculosis, HIV/AIDS, and malaria. Since 2014, the Global Fund has started funding Indonesia's TB control

rise to two significant issues. Firstly, there is underreporting of TB cases due to a lack of coordination between the NTP and the private provider (Rakmawati, Hinchcliff and Pardosi, 2019; Paskaria *et al.,* 2022). Secondly, individuals who seek treatment at private clinics often face high patient costs. Since the study is centred on the latter, I will go into more detail about it in the next section.

Numerous studies have delved into the costs associated with seeking treatment in Indonesia, consistently demonstrating that patients who initially seek care from private providers incur higher pre-diagnostic cost.[6] These costs arise primarily due to multiple pre-diagnostic visits, travel expenses, and hospitalization (Lestari *et al.,* 2020; Fuady *et al.,* 2020b; McAllister *et al.,* 2020b). Two key factors drive this issue. Firstly, private doctors' lack of confidence in diagnosing TB due to unfamiliarity with national TB guidelines results in multiple pre-diagnostic visits and diagnostic delays (Ku *et al.,* 2020; Lestari *et al.,* 2020).

Secondly, regarding financing coverage, National Health Insurance scheme (*Jaminan Kesehatan Nasional*, JKN) oversees the financing of the demand side of TB, which pertains to clinical care through a capitation system. In contrast, the NTP is responsible for financing the supply side, which includes the procurement of drugs and diagnostic equipment (WHO, 2022). While JKN has established links with private providers and is gradually expanding to enable them to offer free TB care, a regulatory bottleneck exists from the supply side. NTP funding for diagnostic equipment remains biased towards public providers, hindering private providers' ability to provide point-of-care testing facilities (ibid p. 137). As a result, presumptive TB patients in private providers are often pushed to seek testing outside of the facilities they initially visited, leading to increased patient costs.

However, the details remain ambiguous, so this interpretation should be trodden carefully. Besides the joint reports from the NTP, Ministry of Health, and the WHO, there is a notable scarcity of studies that delve into the politics and regulatory framework of the TB public-private mix in Indonesia, particularly regarding the effects of regulatory barriers on the provision of TB care in the private sector and, in turn, patient access to TB care.

[6] Pre-diagnostic visits here refer to various diagnostic visits (e.g., chest x-rays), consultation, or hospitalization before TB diagnosis is established.

4.2 Directly Observed Treatment (DOT) and Decentralized TB Care

While TB control is carried out in all healthcare facilities, the majority of cases are typically managed at the primary level through Puskesmas. Puskesmas carry significant responsibilities in the realm of TB control. They are tasked with the prevention, diagnosis, treatment, monitoring, and reporting of TB cases at the sub-district level. This implies that they play an active role in facilitating the delivery of TB treatment through DOT (Directly Observed Treatment) at the community level (Kementerian Kesehatan Republik Indonesia, 2016). DOT is a TB case management strategy that has been endorsed by the WHO since the early 1990s. Its purpose is to enhance treatment adherence among TB patients by mandating that they take their medication under the observation of designated health workers, community volunteers, or family members (Karumbi, Garner and Karumbi, 2015). Indonesia has embraced the DOT strategy as an integral component of its NTP since 1995.

Another critical aspect of the NTP is the decentralized care model, which serves as a fundamental principle in the country's efforts to manage TB, although its full implementation remains incomplete. This model entails the transfer of care and treatment from secondary healthcare facilities, including public/private hospitals and specialized hospitals, to primary healthcare facilities such as Puskesmas or clinics (Noerfitri *et al.,* 2019).

According to a study conducted by (Ho *et al.,* 2017), which assessed the effectiveness of the decentralized model for DR-TB patients, locally delivered care has the potential to eliminate certain barriers to treatment adherence, notably those related to transportation and hospitalization often encountered in distant centralized care settings like hospitals. Additionally, this model promotes stronger support from a patient's social network, which can enhance the likelihood of treatment adherence. Ultimately, the core aim of this model is to ensure the accessibility of TB services, with a specific focus on the entry points of the healthcare system, where patients initially seek medical attention. This approach is particularly relevant for DR-TB patients, as they typically encounter substantial patient-cost, particularly transportation and hospitalizations.

Nonetheless, implementing decentralized TB care for DR-TB patients remain a significant challenge in Indonesia. Historically, care for DR-TB patients has been predominantly provided in hospital settings due to their susceptibility to adverse effects that often require specialized attention, and the risk of non-compliance to the stringent treatment regimen. Consequently, patients have

been primarily referred to and treated in Programmatic Management of Drug Resistant-TB (PMDT) services, which are predominantly hospital-based. Only recently has the Ministry of Health introduced decentralized care for DR-TB patients.

Under this new approach, patients who have initiated treatment in hospitals without complications or drug intolerance can be transferred to satellite health facilities (e.g., Puskesmas) nearest to their place of residence (Kementerian Kesehatan Republik Indonesia, 2020a). However, the expansion of this program is significantly hindered by the absence of a dedicated budget, stemming from the lack of political commitment at the sub-national governance level. This limitation ultimately constrains the capabilities of Puskesmas, particularly in terms of facilities and personnel in providing care for DR-TB patients (WHO, 2022).

In short, both DOT and decentralized TB care represent the bedrock of TB control in Indonesia. However, the progress of these programs is impeded by fragmented public financing and insufficient political commitment.

4.3 Non-State Actors in the Indonesia National TB Programme

Another crucial element of the NTP is the involvement of TB activists (e.g., cadres and patient supporter) who typically collaborate with Puskesmas or PMDT hospital for health promotion and the supervision of patient treatment. Cadres and patient support actively assist healthcare workers in TB case management and monitoring of TB patients within their specific areas of operation. While TB cadres are often people assigned by Puskemas, patient support representatives are people employed by CBOs operates within particular areas and they may have some sort of official contract; both works voluntarily and seldom get monetary compensation(WHO, 2022). Their main responsibilities include accompanying patients during medical examinations and providing reassurance to help patients overcome any reluctance to disclose their TB status, thus reducing the risk of treatment discontinuation or therapeutic failure. The social and educational aid offered by cadres and patient supporters plays a pivotal role in addressing barriers to treatment adherence, particularly those stemming from social marginalization due to stigma and discrimination. These challenges can be influenced by social and cultural structures within a given community or setting (Munro *et al.,* 2007).

Apart from government health facilities and private hospitals, CBOs also have a vital role in TB control and are integral members of the NTP's network. While health facilities mainly handle the immediate health requirements (upstream) of individuals, including the provision of medical care, diagnosis, and treatment, CBOs primarily focuses on addressing the broader social and economic dimensions of TB, as well as behavioural factors (downstream) by providing socioeconomic support and raising awareness (Kementerian Kesehatan Republik Indonesia, 2020b).

This is not to imply that health services particularly Puskesmas are solely responsible for the medical aspects, while CBOs contribute to non-medical holistic care. Both actors have their own roles, but it's essential to highlight that both actors possess the capacity, often facilitated by financial autonomy and organizational capacity, to extend their care contributions beyond their commonly recognized 'standard' responsibilities.

5. Household Burden a View from the Frontline

5.1 Prevailing Household TB Burdens

Before moving into the role of the family in providing protection, it's critical to understand the type of burdens related to TB that this protection frequently seeks to mitigate. Based on several interviews, if someone becomes ill as a result of TB or the household will often use their savings or income from assets to fund any necessary expenses associated with TB treatment. When I asked where the resources usually went for additional expenditures, the two most common answers were food and transportation.

Generally, there is a common perception that a protein-rich diet, specific for TB, poses an additional burden, but not to the extent that it significantly affects treatment recovery. However, an interview with Amin (patient) and his sister Fatimah (family member, sister) indicates that the perception of how additional expenses on food and maybe other necessities affect both treatment recovery may be different between patient and family member.

Amin and Fatimah are siblings who originate from severely impoverished families and are among the 25% poorest families in West Bandung Regency.[7] Amin has 11 siblings, including Fatimah, and he initially contracted TB while working as a construction worker, which was also his prior career. Amin primarily relied on his family, who mostly worked as manual laborers and particularly his 80-year-old farmer father. Fatimah is one of the family's daughters who occasionally accompanies Amin to Puskesmas since Amin cannot attend alone owing to his special needs condition which requires additional supervision from family members.

When asked about the impact Amin expressed that added cost for foods did not necessarily disrupt his treatment recovery, whereas Fatimah did not provide the same conclusive response. Instead, she explained that additional dietary requirements were often tied to daily income. She acknowledged her family's inability to consistently supply protein-rich diets for Amin due to fluctuating daily income.

> "There isn't any problem, because my father is growing rice. So, we have rice at least, Alhamdulilah, although it's not much, it's only a little. On the other

[7] Three informants receive financial transfers for non-food items (BPNT), (Amin and Fatimah, Fadimah, and Rizki). The primary eligibility criteria for this assistance is 25% poorest families within regional social welfare data.

side (of the rice field) fishpond is being built. It's not too difficult to eat… even though sometimes there aren't any *lauk* (dishes like meat or fish eaten with rice), so it's mostly only rice, it's okay though." (Amin, DS-TB patient, 7 August 2023)

"If we have money, we can buy milk or other needs for him, but only if we have (the money). The thing is my father is very old, he still works. If he feels strong, he will go to work, if he doesn't, he doesn't work. I also can't take care of him (Amin) myself because of my condition too." (Fatimah, sister-family member, 7 August 2023)

I also noticed a similar response when I chatted with Rizki, a mother and family member of a DS-TB patient named Rifki. Rizki, like Amin and Fatimah, comes from one of the 25% poorest families in Bandung City. She is the breadwinner in the family, with the majority of her earnings coming from the small shop she runs with her relatives. The son Rifqi quit his job as a manual labourer and is currently unemployed while undergoing therapy. When I asked if she had any difficulties during her TB treatment, she did not indicate openly that she had, but rather answered in an uncertain tone, "*For food, [we] just eat what's available… but it's just that food is a bit difficult because you need nutritious food, you need money for that, before this it was simple*."

What is interesting from this conversation is that when Amin shared about his challenges during treatment recovery, he didn't perceive food as a significant disruption, Fatimah on the other hand shared that the family struggled with providing continuous dietary assistance for Amin, indicating a level of disturbance in Amin's treatment recovery. When I asked this question, I assumed that patient, particularly those from lower-income households, would see the increased expense of food as a potential barrier to their treatment recovery, as numerous studies have claimed food to be a major hindrance. However, I was informed about this dimension of the problem by a family member informant. This is a viewpoint I would have expected to be more prominent from the patient's standpoint rather than the family's.

In addition to food expenses, transportation is also one of the costs that generally arise and may pose a problem. Most of the informants, both patient and family, mentioned that they had to cover their transportation expenses with their own pocket money, usually referred to as *uang bensin* (gas money). However, this did not pose a significant burden because they lived close to the Puskesmas and did not need to make frequent visits. Typically, after treatment initiation drugs were administered once a month with the occasional visit if the patient had a side effect.

"For financial (impact)… alhamdulilah, because we use BPJS (national health insurance), so we get free medicine, and the distance between my house and treatment (facility) is not too far because we take the closest one." (Didi, DS-TB patient, 3 August 2023)

The relatively low number of participants who mentioned transportation challenges can be attributed to the implementation of decentralized TB care services and the utilization of DOT and Self-Administered Treatments (SAT). The introduction of DOT/decentralized TB care has made it easier for patients to access treatment at their nearest Puskesmas, eliminating the need for them to travel to distant specialized hospitals (Zawedde-Muyanja *et al.,* 2021; Inayah and Wahyono, 2019). Additionally, the SAT approach, which involves patients' families and TB cadres, has reduced the number of required visits to healthcare facilities. These combined efforts have contributed to the reduced transportation difficulties faced by participants (Puspita *et al.,* 2019; Steffen *et al.,* 2010).

However, this does not indicate that there are no patients who have transportation issues. Some patients require many pre-diagnosis visits before being referred to Puskesmas and beginning treatment. For example, according to his sister Amin had to go on multiple visits to the hospital before being referred to have tests done in the Puskesmas, pushing the family to go into debt to their neighbourhood.

Fatimah: "Sometimes we need to borrow money first, like yesterday, he needed to go to the hospital, so we need to accompany him right, so we borrow money from the neighbourhood to cover the expenses.

Salma : For transportation?

Fatimah : Yes. Because mom and dad don't work, and I also don't have money because of my situation and also most (family members) work in construction. Everybody is working as *kuli* (construction worker), no one has permanent job, no one, everybody is *kuli.* – interview with Fatimah, family member, 7 August 2023

Then there's Tuti, a former TB patient from Tasikmalaya district/regency who had visited a doctor on multiple occasions in Puskesmas but had never been diagnosed with TB despite the fact that the Pukesmas has a TB program. She was eventually diagnosed with pulmonary-TB after her relatives suggested she get a chest X-ray in the city.

"I have been to the Puskesmas four times, five times if I'm not mistaken. They said it's because of the weather, coughing due to the weather. It was similar

> to this weather, raining at that time. But why doesn't my cough stop? Usually, when given medicine, it stops. But people say, if you have lung diseases, you often cough and, but I didn't have cough. Also, my chest wasn't hurt. When I had an X-ray in Tasik (Tasikmalaya), apparently, I had fluid in my lungs." (Tuti, former TB patient, 5 August)

Amin and Tuti are two of the few patients that have notable multiple diagnosis visit and transportation burdens prior to starting treatment. This finding is similar to that of McAllister *et al.,* (2020) who discovered that some patients require multiple visits to healthcare providers before receiving TB diagnosis due to a variety of reasons such as limited access, delayed symptom recognition, seeking care from multiple providers, lack of awareness among health workers, and general TB diagnostic challenges. This ultimately contributes to the entire patient cost but is often overlooked by TB catastrophic cost measurement because the measurement gravitates more towards the expenses incurred after the diagnosis.

Furthermore, transportation costs still pose a significant burden for DR-TB patient. The key factor that distinguishes DS-TB from DR-TB is the frequency of visits to healthcare facilities. This difference arises because not all Puskesmas provide DR-TB services as some aspects of services are not decentralized. As a result, patients often need to travel to PMDT hospital that are quite far from their place of residence, adding an extra layer of financial strain and logistical complexity to their treatment recovery.

> "The most difficult stage, especially economically, is the treatment. We were essentially helpless, especially during the first year. I was too weak to work and couldn't even afford to start the motorbike. For the first two weeks I was treated in hospital, but because it's too far away, I asked to be transferred to the nearest Puskesmas. The (hospital) polyclinic eventually gave permission. In the third week I was moved to Puskesmas. That's where I stayed for four months, visiting every day with *ojek* (motorcycle taxi) because I couldn't ride a motorbike and had no energy at all. It was exhausting." (Kura, former MDR-TB patient, 5 August 2023)

6. Tuberculosis Welfare Ecosystem

In order to be able to better understand the welfare dynamics in families affected by TB, adopting the perspective of informal social protection can offer valuable insights. This approach allows us to delve into two key aspects: the strategies employed by households and the resources available to them, as well as the often-overlooked burdens that transcend individualistic measures (i.e., catastrophic costs/cost of illness). To start we should first identify how informal social protection manifests within the TB welfare ecosystem. (Mumtaz, 2022) conceptualization of informal social protection, which centres on the provision of social assistance by non-state entities, will serve as our guiding framework to explore the various types of providers present in the context of TB. Through this mapping process, we can identify not only relevant actors but also their underlying mechanisms: whether they serve as sources of immediate relief, coping strategies, safeguards for human capital or the labour market, or even mechanisms for risk-sharing (Mumtaz, 2022; Oduro, 2010).

6.1 Family

6.1.2 Kinship claims and material burden

Households often receive significant social assistance from both immediate and extended family members when a family member falls ill. Intra-household transfers involve resource mobilization within the household, while extra-household transfers entail resource mobilization across different households, such as assistance from extended family members or friends. This access to network resources is, as mentioned earlier, refer to as social capital. This system is often based on kinship claims where entitlement is derived from familial bonds or affinity.

Household members typically use their savings or assets to cover medical or other household expenses, and this financial resource is often complemented with intrahousehold labour substitution. Based on a few interviews with patients and family members, it's common to see mothers taking on both provider and homemaker roles during a health crisis—this aspect will be elaborated in section seven. This coping strategy might be adopted either as a means to compensate for a loss in income caused by TB or to meet household necessities amidst the sudden increase in health-related demands.

Furthermore, when a family possesses a robust support network, particularly from their extended family, they may resort to extra-household transfer. Based on interviews, such transfer usually manifests in monetary forms, such as borrowing money or cash donation, but it can also include non-monetary forms, like labour assistance in the form of caregiving substitutes or even adequate housing support which is particularly important for TB. Nevertheless, this option, particularly borrowing money, is typically considered a last resort, only pursued when internal household resources are entirely depleted.

Extra-household transfer typically serves two primary roles. Firstly, it functions as immediate aid to address pressing medical needs, such as covering the costs of chest X-rays or transportation to health facilities. Secondly, support from extended family members can also act as a measure to mitigate welfare losses resulting from exogenous health shocks. For instance, extended family may provide support for children's education to ensure that it's not disrupted.

> "I was worried about where to get the money (for diagnosis). Eventually, my husband borrowed from relatives; it was around RP. 600.000 ($38) at that time. For the X-ray and transportation costs." (Tuti, former DR-TB patient, 19 July 2023)

> "It's just that my sister's house is big, it's in residential area, and on the above floor there are four rooms. When my daughter was 7 years old, she wasn'r living with me. At that time, she was with her grandmother in that big house, it was owned (together) with my sister. My sister also has a kid the same age as my daughter." (Ismi, mother-family member, 2 August 2023)

> "Yes, the impact is indeed very heavy, the first impact is that there is no work, you just have to go all in for treatment. The second is that there is no income and there is a great need for my daughter education, she was at the end of semester 7 or 8… but yes, my relatives were helping me, for example, for that education cost and for the dormitory too. And also, food, but for food we have it somewhat cover with my wife's stall sales… and also for other routines (university activities) like that. On average for all that, the education cost, the routines, the food, and also for buying books, that cost us a total of about 500.000 ($32) monthly. And also, I still have to pay for my treatment here… so yeah, it's really hard." (Hari, former DS-TB patient, 7 August)

6.1.3 Psychosocial support and emotional burden

One crucial aspect of family support, particularly coming from immediate family, for TB patients is that it extends beyond financial aid; it encompasses psychosocial care, particularly in the form of care and encouragement. This emotional support plays a vital role in motivating patients to adhere to their treatment regimen and bolsters their mental aptitude in facing the mental challenges posed by TB. Some interviewees who received strong family support emphasized that this aspect was crucial in their recovery, even more so than the financial assistance itself. This psychosocial care is derived from the attentiveness of one's family members, including reminders to eat and take medication on time, accompanying the patient to Puskesmas, and even the mere presence of a family member can be a motivating factor for patients.

> "You see, even though I'm getting older, I still have a strong will to live. For what? I still have my children, where would they be in the future, where would they be. They are my motivation. I may be old, but my children who depend on me still need a lot of guidance, attention from the family. That's where my motivation comes from, that's what keeps me going." (Ahmad, DS-TB patient, 31 July 2023)

Conversely, the lack of family support can influence patient's treatment adherence, particularly in facilitating the process of stigmatization. The stigma surrounding TB is widely acknowledged as a major barrier to care access and treatment adherence and family plays a major role in mediating the stigma. Family members, as well as the community, can reinforce stigma through their beliefs and direct/indirect behaviours such as verbal gossip. This can result in internalized stigma among TB patients and symptomatic individuals and can further lead to self-isolation and negative psychological effects such as low self-worth and depression (Pradhan *et al.,* 2022; DeSanto *et al.,* 2023). These detrimental impacts can ultimately deter a patient from seeking care or continuing their treatment.

Among patients that I have interviewed two DS-TB patients informed me that they "separate utensils from family members" and "self-isolate" as what they perceived as precautionary measures to prevent close contact transmission and that they learned mostly from their family and friends, as well as nurses.

> "Yes, I'm still my husband, but like also wearing a mask so it's not contagious, and I also don't put plate and glass together with others, that's what doctor said. But what is hard it's because, I can't socialize with other people, so

basically you close yourself off… because I'm afraid of other getting infected too. So, know I rarely gather with others… I used to gather with people a lot back then." (Emas, DS-TB patient, 31 July 2023)

"I think it's the fear. People didn't isolate me, but they kept the distance and wore mask, they were worried of getting infected. But you know, I also need to be considerate, I need to keep my distance from my children and wife. I was told by the doctor to be extra careful especially around my close family. With plates and drinking cup, they also need to be separated." (Hari, former DS-TB patient, 7 August 2023)

Both Emas and Hari expressed that they didn't receive or feel any differential treatment from their family members and that their willingness to separate utensils and self-isolate came from their own "self-awareness" (*kesadaran diri sendiri*). What sometimes misses when inspecting "self-awareness" is that it's also come from the idealization patient's right behaviour that stems from social actors such as family and community (Freitas *et al.,* 2012; de Lima *et al.,* 2001).

While only two DS-TB informants experienced internalized stigma almost all of my DR-TB informants experienced a heightened degree of stigmatization. They perceived that stigma primarily came from strain on family cohesion due to the debilitating impact of DR-TB that in most cases results in long-term welfare loss and increased care burden which ultimately put tremendous stress on the family.

To give some local context, what seems to distinguish the degree of burden between DS and DR-TB cases according to my informants is prolonged income loss and transportation costs derived from longer treatment periods. Three of my DR-TB informants (Desi, Tita, Kura) who reported experiencing significant welfare loss and mental stress were those undergoing a long-term (22-24 months) injectable-based treatment regimen. They were required to visit the *Hasansadikin* hospital one of the PMDT hospitals in West Java for five days a week during the intensive phase, which typically spans 4-6 months. Even as they progressed to the advanced phase of treatment, the patients still had to make regular visits to health facilities for medication and evaluations. This financial and care burden eventually becomes so pronounced that some patients are compelled to return to their parents' homes because they can no longer sustain themselves or their families. In my interview with Kura, a former MDR-TB patient who was forced to quit his job without severance pay, he

suspected that the decision to return to his parents was one of the reasons his marriage relationship deteriorated.

> "Sometimes I felt this (uneasy) feeling coming from my spouse. Although for me, I trust and rely on 100% towards my parents during treatment, because during the treatment I lived with my parents. I intentionally moved from Bandung Regency to Bandung City because TB treatment in Bandung City had been successful before. So, I moved to Bandung City. When I first had TB in 2000, the treatment lasted for the usual six months. Then, in 2015, I moved to my mom's house for TB treatment. After moving, I began to notice there were these seeds of problems with my spouse." (Former MDR-TB patients, Kura, 5 August 2023)

From the interview with the three MDR-TB patients there seemed to be a consensus that income loss is a major factor that pushes them to further socioeconomic deprivation. This finding is similar to a qualitative study conducted in South India that by Rubinstein and Blumenfeld (2023) found in the perspective of the caregivers change in treatment is due to gradual livelihood degradation emanating from financial burden and lack of resources to cope and emotional distress, and stigma induced by DR-TB treatment can lead to family conflict. Consequently, this paradigm is frequently used as a popular approach to formulate particular social protection programmes aimed at compensating for income losses.

Before engaging with my informants, I also share similar assumption, that income loss is the uppermost risk factor that could trigger further deprivation among TB-affected households given the fact that men are the primary providers in most Indonesia household arrangements. So, supposedly when men, or the primary provider, falls ill the household would be more susceptible to family conflict. However, a conversation with former DR-TB patients Tita shed some light on how even without financial impacts TB diagnosis and treatment can still co-occur with family conflict.

During periods of treatment Tita was a housewife with two children. Despite coming from a single-income household she reported little financial issues besides the additional cost for TB-specific diet and travel. Similar to Kura, Tita also decided to move out to her parents' house because she needed extra support in terms of supervision and particularly emotional. During the treatment period, her husband provided very minimal assistance and seemed

indifferent to Tita's recovery. When asked what might have caused such an indifferent response, Tita answered because of the stigma surrounding TB and because, as she quoted, "*my husband had the choice to care but chose to be indifferent*." This dismissive response ultimately strained their relationship and renders a very heavy mental burden for Tita.

> "It's (the lack of support) more on the side of my husband, you see. It might be because he lacks education, but no, it's like he doesn't want to be educated. Like, when I go for my check-ups, he does come along, but he doesn't care about it. Maybe it's because the impact of these treatment obstacles, it influenced him. At some point he even thought about giving up (marriage), but maybe because of his parent's advice, they said something like, "you shouldn't leave a sick person alone," so maybe my husband had second thoughts. But it's not that he lacks education; it's more like he's indifferent, and the impact is pretty much like that." (Tita, former MDR-TB patient, 5 August 2023)

They both mentioned falling out of their treatment at some point throughout their conversation. Encouragement from their family then motivated them to continue and complete their treatment. Kura stated that his parents' support was crucial in keeping him going, whilst Tita believed that her two children, in addition to her parents, provided significant moral support. In fact, Tita believes that her children are the most encouraging source of encouragement, even when no material contributions are made.

She shared an experience in which she felt that her mothering duties, such as preparing food for her children, and even interruptions, such as her children waking her up from sleep, reminded her of a semblance of normal life outside of being an MDR-TB patient. She didn't see this interruption as an inconvenience or problem that may hinder her treatment, but rather as a reminder of why she needed to continue with her treatment.

> "I just realized that my youngest child, who was still in the first grade of elementary school, used to disturb me when I was sick. When I finally recovered, I just realized that: oh, it turns out this child was the one who motivated me to recover. So, in life, nothing is easy. I thought, "Oh, it means my childred are the reason I became strong." Because they disturbed me, and when I was sleeping for a long time, the kids would disturb me, and I would wake up. But I took the positive thinking, "Oh, it means I shouldn't sleep too long, not to be

> complacent." So, when I recovered, I just realize that there were many blessings. It turns out, children gave me many blessings, like angels. Alhamdulillah. There is meaning on why they disturbed me." (Tita, former MDR-TB patient, 5 August 2023)

Provision of psychosocial care is an aspect that is often overlooked in discussions of informal social protection. While the prevailing rhetoric on social protection primarily focuses on what may termed risk mitigation, there is a noticeable gap in addressing the potential psychosocial dynamics that may arise when resources are mobilized. Baig and Chang (2020) have shown that social networks, including family and friends, can provide vital support for the psychological needs of migrants, while Mokomane (2013) mentions the provision of psychosocial care given my mother within the family. This form of protection is strongly present due to the inherently emotional and care nature of social relationships, but most discussions remain fixated upon household consumption, leaving non-economic components largely unattended. This result is a significant blind spot when it comes to analysing the emotional, care and gendered aspects of informal social protection.

6.2 Community Assistance: Puskesmas and Community Based Organization (CBO)

Another significant source of informal protection comes from the community, particularly through CBO and Puskesmas. The CBO I engaged with has been active for five years with a specific mission to support DR-TB patients. They collaborate closely with PMDT hospitals and deploy patient support personnel who monitor and offer emotional support, and TB information to patients and families. While Puskesmas provide medical care, they also offer social assistance to patients they identify as at risk of treatment dropout.

One of the most prevalent forms of support for TB patients is the 'enabler' assistance program. This program is funded by the Global Fund but administered locally by a CBO. The enabler assistance involves an unconditional cash transfer of 600,000 ($39) per month, with a focus on incentivizing MDR-TB patients to complete their treatment. The primary purpose of this assistance is to compensate for indirect costs, especially related to transportation.

The enabler scheme has a single inclusion criterion, which is the patient's DR-TB status, irrespective of their economic standing. According to interviews with CBO staff this has resulted in instances of 'rejection' from eligible patients. This rejection was primarily due to patients' perceptions that they didn't require

the assistance. These perceptions often stemmed from their upper-middle-class backgrounds or religious beliefs, where they felt the assistance should be directed to individuals facing more significant needs.

> "For example, if someone is religious, they might refuse. I've had assistance from a company through our foundation, and this person said, "No need, give it to someone else." I said, "It's okay, this is your rezeki (blessing)." If they want to give it to someone else, that's fine since it's rightfully theirs, but they refused, there are some case like that." (TT, CBO staff, 5 August 2023)

Furthermore, local CBO also administers additional support programs for DR-TB patients, with a focus on ensuring treatment adherence, providing family education, and patient economic empowerment. They have their own financial aid initiatives and patient empowerment programs funded through corporate social responsibility (CSR) contributions from companies, hospitals and religious institutions. To determine the recipients of financial assistance under their program, the local CBO establishes specific criteria. They conduct assessments of the recipients' welfare, examining aspects such as the condition of their homes, family background, and the patient's role within the family (e.g., whether the patient serves as the primary breadwinner)—something that seemingly missing from the enabler scheme.

> "When it comes to assistance from others, it's usually from foundations like ours, you know. We look for donors from the private sector, and Alhamdulillah, we can give patient small assistance. Alhamdulillah, it's been running for 2 years now, but it's limited in providing aid to MDR-TB patients. They only give 2.5 million per month, so 500,000 ($32) per patient, so Alhamdulillah, it's quite helpful. But because there are still many patients in West Java who are out of our reach, you know." (DS, CBO staff, 18 July 2023)

An interesting facet of this assistance program is the patient empowerment initiative, which offers initial capital to help individuals start their own salted egg businesses. The donor behind this program remains unidentified, whether it's a public entity, private organization, or philanthropic foundation. The primary objective is to boost the financial independence of DR-TB patients and increase their productivity by enabling them to establish their own businesses, thus reducing their susceptibility to catastrophic economic events. However, the business model implemented fails to generate a significant surplus that would substantially benefit the patients, leading the CBO to ultimately discontinue the program.

> "Then, we also recently had a collaboration to empower patients, we provided capital for patients to make salted eggs, to empower them. Unfortunately, it didn't continue because the one who provided the capital was very hesitant. Making salted eggs involves a two-week process, from production to harvest. Let's say we have capital of RP. 500,000 ($32) for one harvest. Then, we spend it, and we have to wait another two weeks. During those two weeks, where do we get income? So, most of the capital is used up, and any profit's also gone." (Desi, CBO staff, 18 July 2023)

In the case of Puskesmas, they have less incentive to provide social assistance due to institutional barriers. However, social assistance typically provided by Puskesmas is more integrated into district health policy programme because it often results from multi-stakeholder collaboration involving health centers, hospitals, health offices, and philanthropic organizations and have formal deliberation. As a result, social assistance is sporadic and is primarily initiated by the local health office. The aid given typically consists of cash transfers or basic food assistance and doesn't involve specific criteria such as enabler schemes.

Puskesmas also have a degree of organizational autonomy, allowing them to make decisions like waiving fees for general patients[8] who are presumptive TB, allowing them to commence treatment rapidly. This autonomy is made possible by the capitation system introduced during the decentralization of Indonesia. However, it's important to note that not all Puskesmas are willing to provide such assistance. In the case of Puskesmas in West Bandung Regency, this kind of assistance is notably absent.

In the case of Bandung City, the Puskesmas stands out as having one of the most robust TB control programs in Bandung City. The health worker who was interviewed has over 20 years of experience in TB control, demonstrating extensive knowledge and heightened awareness of TB. Beyond providing medical care, she also actively advocates for the rights of vulnerable TB patients within the Puskesmas management to ensure that patients are accepted and receive the necessary treatment. Additionally, she also actively works together with TB cadres to seek assistance when TB patients face challenges in accessing treatment, such as arranging transportation to the Puskesmas. This highlights how access to care can also be influenced by health workers.

[8] General patient is referring to patient that doesn't enroll in BPJS Kesehatan program (Badan Penyelenggara Jaminan Sosial Kesehatan, Social Security Agency on Health)

> "We discuss it with the management, you know? We have the head of the Puskesmas and sometimes we talk about the obstacles or issues that patients are facing. In the end, Puskesmas can at least help (in terms of waiving charges), whereas it might be different for hospitals because they have to meet certain managerial requirements. Even though there are many challenges, we will try. We are responsible for ensuring that the patients can receive treatment. If you want to know, there's a story. We once had an MDR patient, and we opened a donation campaign at the Puskesmas. "Maybe there are some people who want to help," and we share it in groups, especially when the condition is critical and urgent…" (Devi, nurse, 12 August 2023)

6.3 State Assistance: Cash Transfer

Apart from free treatment so far Indonesia has yet to have a TB-exclusive or inclusive social protection policy, but some patients do receive monthly cash transfers through non-cash food assistance (*Bantuan Pangan Non-Tunai*/BPNT). Out of the 14 patients and family members who were interviewed, only three (Fadimah, Rizki, Amin and Fatimah) received this scheme, as it's only eligible to the poorest 25% of families within each region. Prior to TB, they already received rice and cash assistance totaling RP. 200.000 ($13) per month. Following the scheme's aims, this assistance is generally used to meet the food needs of families.

While BPNT is not specifically designed for TB, it's worthwhile to delve deeper into how this support might serve as a buffer for the economic impact of TB on households. I proceed by contrasting the experiences of patients and their families regarding the role of BPNT in addressing the burdens associated with TB, particularly for nutritional support.

Despite the fact that all of the families are from the "poorest 25%," when I inquired about how beneficial the assistance is in covering additional expenses induced by TB, the responses varied from indifferent to perceiving that the assistance is not nearly enough. The difference in perceptions can be attributed to two factors: household size and collective ability to generate income (see table below):

Table 2 Informant perception of BPNT on TB impact

Informants	Household characteristic	Perceptions of BPNT in offset TB impact
Rizki	- Female-headed household - Income fluctuates and primary income from a small shop - Productive member of the family is ill (income loss) - 5 household members (mother, son, daughters-in-law, and two grandchildren)	Rizki: " Yes, sometimes I get rice and around RP. 200,000 ($13) a month. Actually, I've been receiving this assistance for a long time (before my child contracted TB). Salma: "If I may know, how helpful is this social assistance during TB treatment?" Rizki: "It's okay. I just don't make anything complicated. If we want to eat, just eat whatever is available."
Fadimah	- Double income household - Primary income from husband selling porridge, secondary income from wife - Non-productive member of the family is ill (no income loss) - 4 household members (husband, wife, and two daughters)	Fadimah: "Alhamdulilah. It's enough. Because I'm a seller so I don't have a fixed monthly salary. So it really depends on a daily basis, if, for example, I make sales, I earn something; if not, then I don't earn money. But Alhamdulilah with this assistance for example if I'm take a day off, it helps with the daily needs. I don't have to buy rice again. Also, it (the assistance) can be used for porridge. I can use it to fund for my porridge business. Alhamdulilah."
Amin and Fatimah	- Working poor household (almost all family members are working but in a precarious condition) - Income fluctuates daily	Fatimah : "Because he often feel hungry. So, it's a bit lacking (the assistance). If the assistance is not enough. And then later, if, for example, the TB is cured, he wanted to go to the hospital for rehabilitation... how could he? So yes (the impact) is quite significant. The cost, for example, because we often feel hungry, that's how it's..."

	- Productive member of the family is ill (income loss) - 11 household members	

The table above illustrates that even within the poorest 25% of families, there is a gradient of family conditions that play a crucial role in determining their vulnerability, particularly when confronted with emergencies like TB.

If we were to adopt BPNT as a model for TB-inclusive formal social protection policy, in the spirit of avoiding catastrophic expenditure, it would be fairly challenging because the aid is very likely to be utilized for other family needs, especially for impoverished households with multiple family members. This is reflected in the differences in experience between Fadimah and Amin, and Fatimah. Despite both being in the poorest quartile of households, Fadimah's family were able to endure treatment due to the household's greater financial capacity (double income) and fewer family members.

Even for households receiving the BPNT, alternative sources of income in the family were crucial to financing TB treatment and recovery. In the context of Fadimah, for instance, the regular earnings generated by the porridge business covered the financial requirements for everyday needs and additional costs arising from TB. As a result, cash transfer assistance continues to be utilized in a manner consistent with its intended purpose – as an income supplement that can help households address food insecurity and stimulate the growth of microbusinesses.

In contrast, in the situation involving Amin and Fatimah, the family exhibits heightened susceptibility due to pre-existing circumstances. Individual family members typically engage in self-employment with precarious working conditions. In an interview with Fatimah, it was found that BPNT assistance was utilized to address Amin's dietary requirements. However, the assistance provided was deemed insufficient due to the necessity of allocating it among other family members, given the presence of inconsistent income.

Only three of the 14 informant patients who sought care at the Puskesmas received BPNT assistance, is another aspect that might be significant. Granted that Amin and Fatimah, Rizki, and Fadimah are among the statistically 25% poorest households, meaning they are statistically more vulnerable than other patients; nevertheless, this does not account for the reality that a large number of other patients also subjected to heavy socioeconomic impact as highlighted

on how the resort to extra-household transfer such as borrowing money. Furthermore, some households that affected with TB such as Amin and Fatimah, as well as Rizki, are more vulnerable to diverting assistance to fund increased healthcare costs.

6.4 Conclusion

The experience of TB patients in this study highlights substantial reliance on family support throughout treatment and recovery. Although the community and the state also play a role, their assistance is conditional and limited. In most cases, patients still depend first and foremost on their family for support. By adopting a regime-focused approach, we can attribute this phenomenon to the absence of state-based welfare provision. Consequently, this leads to a shared responsibility between formal (state) and informal (household) sources of support (Motel-Klingebiel, Tesch-Roemer and Von Kondratowitz, 2005). Drawing from the notion of family from sociology and economics approach, the family is viewed as an interdependence institution, where its members depend on one another for diverse forms of assistance, encompassing both tangible support like joint financial obligations and intangible like psychosocial support. Bridging these two concepts, it's reasonable to conclude that both intra-household and inter-household transfers are required in the absence of state support.

While a regime-based approach can explain the conditions that prompt dependency on informal resources, it may not provide a tool to further understand the implications arising from these dynamics. Wood and Gough's typology of welfare regimes does highlight trade-offs between productivism and welfare in which individuals may prefer short-term security for long-term insecurity. For example, in the absence the more secured welfare provision individuals may resort to borrowing money from illegal means that could lead to future deprivation. However, these points were not elaborated in detail, possibly because the lens used primarily focuses on socio-political macro-level analysis, which tends to limit its scope to the state level. As will be examined in greater detail this lens is also limited in its examination of gender relations within entitlement arrangements, and how gender norms may mediate access to household resources.

7. Gendered Perspective in TB-Affected Household

A crucial feature of TB treatment and recovery that is often overlooked is the gendered aspect of household support for patients. There is a widespread perception in the TB and gender debate that men are more concerned about their economic prospects, such as job and income loss, as a result of their status as household providers. Women, on the other hand, are viewed as more concerned with social prejudice caused by TB, such as social isolation and marriage prospects (Courtwright and Turner, 2010). Furthermore, because women have lower participation rates in the formal labour force, they have less access to finance and frequently become financially dependent on their husbands or family. This financial reliance, combined with domestic tasks that are delegated to women, often leads to women eventually decides to de-prioritize care-seeking (Turusbekova *et al.,* 2022). Consequently, the gendered discourse of TB has been coloured mostly by how gender mediates care-seeking behaviour, whereas scholarship on welfare and especially household-level impacts of TB remains for the most part gender blind.

Numerous studies have shown that gradual welfare losses are often caused by the primary 'bread-winner', in most cases the husband, losing their main income source because of TB (Meghji *et al.,* 2021; Ukwaja *et al.,* 2013; Jackson *et al.,* 2006). Based on interviews with patients, family members, nurses, and CBO officials, it's obvious that when the primary provider is ill, significant adverse consequences such as schooling disruption ensue. As such, the research for this study confirms that income loss is a major risk to household welfare.

However, interviews with patients and family members also highlights nuance to this dynamic. Specifically, in contexts where the husband or the supposed 'sole breadwinner' contracts TB it's the mother in a household who assume the role of income provider. Yet this expanding livelihood role comes in addition the existing role of the mother as caretaker for the household. This finding aligns with the observations made by Sauerborn, Adams and Hien (1996) who noted that intrahousehold labour substitution is one of the coping mechanisms families employ during health emergencies.

7.1 Change in the Household Division of Labour

First, I think it's important to establish what prompted this change in household arrangement. Several male patients stated that they were voluntarily

withdrawn from their work or laid off due to worsening health symptoms. While they were undergoing treatment their daily needs and also their medical needs generally came from the wife's income, predominantly generated from running small shops selling snacks, and beverages. In these cases, the wives usually acted as stay-at-home wife while attending the shop as a side job. They do so to compensate for the loss of income and to address additional needs arising from the TB. Concurrently, they continue to manage domestic responsibilities within the household, including childcare.

> “"Now, my wife is attending shop. Originally, it was initiative because I'm not working anymore. I felt the financial burden, yes, especially now that I don't have a steady income. With the stall, you know, sometimes it's busy, sometimes it's quiet, something like that."." (Saep, DS-TB patient, 3 August 2023)

> “"My wife is selling in the shop for daily needs. For the treatment, it's personal, you know, from personal savings, a little here and there."." (Hari, former DS-TB patient, 7 August 2023)

It's important to note that in such cases, the patients/husbands don't merely remain passive: instead, they typically begin to partially work once they progress beyond the intensive treatment phases, usually after 2 months of treatment initiation and sometimes supporting the small business run by their wife. Looking at Hari and Saep's interviews, patients' motivations for taking on second jobs may differ depending on their position in the family and financial situation (e.g., whether they are the primary provider, if there is an urgent need at the time, if other people are assisting beyond immediate family). Nonetheless, their work intensity remained lower as compared to their wife, and for the majority of the time they still prioritized rest.

> “Before, if someone asked me to change the roof to a building, I'd do it, even though I used to work in textiles. If there was work, I'd do it; if not, I'd just rest at home. There was no steady job. There were burdens, surely, because of many needs. I feel it too. I don't want to always rely on my child because I know sometimes, they have their own needs. To be honest with you, if there were assistance it mostly comes from my cousin. Like this morning, I didn't think of having a breakfast but he then he invited me for porridge.” (Saep, DS-TB patient, 3 August 2023)

> “My daughter needed education, especially at that time she was in final semester of the 7th or 8th into university. Eventually, when I was nearing the end of treatment, I started helping out my wife by selling cosmetics, bags, belts,

> headscarves, and clothes. It was like a side job, something light. A few orders here and there, nothing too heavy. Once in a while, not a regular thing. It's not like I was fully recovered. Once I was recovered, I can travel around Sumedang from 7 in the morning until 5 in the evening."." (Hari, former DS-TB patient, 7 August 2023)

In Hari's case, even after the end of his treatment, he continued working in the informal sector as a clothing seller in the small business initiated by his wife. Simultaneously, his wife assumed both the primary provider and caregiver roles. This discovery suggests an indication that TB, or general health shocks, may lead to prolonged structural changes within households, potentially posing challenges for patients in reintegrating into the labour market. This underscores the need for further studies to investigate the potential barriers that patients with chronic diseases, such as TB, may face in (re)entering the workforce after completing treatment along with the long-term care obligations that come along with the treatment and disproportionately affecting the mother.

7.2 Women as Shock Absorber

As previously established before during health crises intra-household labour substitution is a common coping mechanism deployed during health crises. In this case women, wives, and mothers become the *buffers* against such shock.

Such is the experience of Siti, a wife whose husband had TB and had been undergoing treatment for more than six months—over the intensive phase. Before her husband, Kurnia, contracted TB, Siti was simply complementing her household income by attending a small stall in the street. Unfortunately, right after Kurnia got TB her stall was evicted because a flyover was being built. Soon after, she resorted to running a stall from her house to sell some of the confectionary goods produced by Kurnia. While attending the stall Siti also cared for her husband and one of her sons who recently got into vocational school. When I asked how she felt about this situation she expressed that this is just another responsibility for her as a wife.

> "*Yeah, that's just wife's responsibilities…* indeed, initially my husband was working, and I was attending stall in the street. But now, with my husband's treatment, things have been a bit disrupted. Luckily, our eldest child is working, so we are grateful for the help from that child. However, when the flyover project came, it led to the demolition of our stall in the street, which happened the

same time with my husband's treatment. But for now, we are still able to sell some of the items from the stall in our house. Sometimes, people come to our home to buy things. It's more like that. Currently, my husband isn't able to engage in any activities." (Siti, wife-family member, 4 August 2023).

On the other hand, in Rizki situation, given her economically disadvantaged background, both Rizki and her son had to engage in work to sustain their daily lives. Before his son's TB diagnosis, Rifqi worked as a manual labourer on construction or manufacturing business, while Rizki managed a small shop with her relatives. And following her son's contraction of TB, the entire family's financial responsibilities, which were previously shared between Rizki and her son, now fell solely on Rizki.

"Yes, my child used to work, but not anymore. *I am now the head of the family.* Currently, I'm selling items with my relatives. We take turns, three days each. That's how we make a living. Sometimes, we receive government assistance every month. I get social assistance." (Rizki, mother-family member, 19 July 2023)

Furthermore, a similar dynamic is observed in the scenario where both parents are healthy but the one who's fallen ill is a non-earning family member such as children. In such scenario the mother may potentially tends to work alongside the father in order to cover for additional expenses due to TB. Like, as shown by the case of Fadimah case, a mother with a daughter that was affected by TB.

Fadimah, was initially a housewife and began assisting her husband in selling porridge, primarily because there's a rising needs because her daughter contracted TB, as well as to cover their mortgage. Recognizing that relying on a single income was insufficient to meet these combined needs, she willingly took on extra work beyond to supplement the household income. Even though Fadimah is contributing financially as the second provider, she still bears the primary responsibility for managing domestic tasks, including caring for the children. During her daughter's treatment, she also serves as a medication supervisor (*Pengawas Minum Obat*/ PMO) for her daughter. She accompanies her to the Puskesmas, administers the monthly-dosed medicines, and ensures that her daughter takes medications. When asked about her feelings regarding this seemingly overwhelming situation, she mentioned that it was her choice, and no one, not even her husband, pressured her into taking on this additional work.

> "I am a housewife, but I also have important responsibilities. Initially, we were renting, so we started saving to build our small house, even though it's tiny. So, if my husband helps, I sell porridge using a cart. He uses a motorbike while I use a cart. So, Alhamdulillah, it's like that. It's not that I'm ungrateful for my husband's income, but if possible, I'll do what I can. He always advises me not to do it. When a husband sees his wife pushing a cart, he feels bad, right? But I say, as parents, we have to start from scratch and not burden our children. Especially now that my daughter got TB. So, we must have a proper house, even if it's small. Alhamdulillah. So, I decided to help my husband."." (Fadimah, mother-family member, 31 July 2023)

The perceptions of Siti and Fadimah of their obligations as wives and mothers in the context of TB-diagnosis in their household resonates with a wide literature on the role of women as shock absorber in the case of chronic disease. Gender norms that delegate considerable care work to women mean that in cases of long-term health crises a disproportionate burden for both care and livelihoods often falls on women. These crises exacerbate the already existing gendered inequalities, compounding care work and increasing risk of financial difficulties (FOA, 2023). Thieme and Siegmann (2010) study, highlight that the gendered consequences of household economic stress reflect power asymmetry in rights and obligations of women in a household. That because of their subjugated position in the male-dominated network, women have constrained access to social capital and are often being instrumentalized (p. 731). At-risk households capitalize on the care and livelihoods work of women, yet those same women may not be able to capitalize and benefit from these same relations when crisis strikes them individually which could lead to negative consequences for their well-being and agency.

This dynamic was evident in the case of a mother who contracted TB, in which the household arrangement and division of labour was unchanged. Mother continuing instead the mother continued to uphold her perceived role as caretaker while still carrying out the household responsibilities.

> "Sometimes, you know, it's just a wife's duty.. I insist on doing household chores even though it's not normal for me, like I was (doing chores) crawling, even bathroom to go to the bathroom." (Tuti, former-TB patient, 19 July 2023)

> "Yes, before getting TB, I was healthy and fit. When you have TB, you feel weak and tired. Despite that, I still took care of the house and the children, even when I had TB." (Emas, TB-patient, 31 July 2023)

> "How do I manage it so that when I come back from the hospital, I won't disturbed. So, in the morning, when I feel fresh, Alhamdulilah my weight didn't drop drastically when I had MDR-TB. It was around 60 kg, but , so in the morning, I take care of things around the house, even though it's not much. Then I cook and check if the food is okay, so that it's good for the children. So, in the morning, I cook anything. The important thing is that when the children come home from school, and when I come back from the hospital, they don't disturb me. So, when they go to sleep, I eat. So, I have to get the food ready so if later they want to either eat or want to play, they can do it (eat) without me, with that they don't disrupt me much." (Tita, former MDR-TB patient, 5 August 2023)

Furthermore, another interesting finding is that some female patient's seem to better able utilize extra-household social capital such is the case of Siti. Siti was a former pulmonary-TB patient in 2017 and during her treatment she admitted to also suffering from joint pain and was pregnant, these conditions were constrained her to conduct her daily activities. When I asked how did she manage to resume her duties while in those conditions she stated that she got assistance from her relatives and particulary from her aunt who is also a TB survivor and now a TB cadres, Yayan, as well as from Qur'an recitation women group (*ibu-ibu pengajian*).

> "Yes, that's right (food and daily support) from relatives as well. For example, they sometimes bring food. Also, yes, the women from the Quran study group are proactive. If they hear that someone has been sick for three days and hasn't attended the Quran study group, they'll ask about the condition. If they find out that someone is ill, we all visit and give some money, as much as the Quran study group manage to collect." (Tuti, former-TB patient, 19 July 2023)

> "Yes, that's why, you know. I always keep an eye on it, not because I'm curious about people's lives, not that, but I want to know about their health, their living conditions... their family situation, their family's daily activities. Especially their children's education. Something like this... "why didn't you read the Quran yesterday in the Mosque?" or "didn't you go to school yesterday?" I always like to ask questions like that so I can stay informed... and so that the mother can relax and have peace of mind too. I too have children." (Yayan, former TB patient and family member, 19 July 2023)

Thieme and Siegmann (2010) explained why on the other hand social capital can also help women to cope with hardship. Women seems to be able to better utilize extra-household social capital because it has potential venue for

collection action due to a lower degree of masculine domination due to the shared identity of like-minded women (p. 728). In Tuti's experience this venue is present in the form of a women's only Qur'an recitation women group which palpably exempt masculine presence, and also her relations with her aunt Yuyun whose relationship not only defined by kinhip/familal bond but also shared experience with TB. Within this social relations between Qur'an recitation women group ad Yuyun, Tuti manage to utilize the social capital better.

These two contrasting experiences signify how social capital for women can serve as intermediary that could heightened women's vulnerability while also protective factors for women. In regard to TB and household coping mechanism of intrahousehold labour substitution, such facet oftentimes read as resilience while ignoring the apparent vulnerability experienced by women in the household.

7.3 Conclusion

The TB-induced economic stress, which led to intra-household labour substitution, resulted in a shift in the household's labour division, with the mother assuming on the combined responsibilities of carer and provider. Icot Thieme and Siegmann (2010) suggest that because women's relationships within the family are subjugated due to gender norms, as such they are unable to effectively utilize the intra-household resources, which leads to a change in household structure. As a result, women are more likely to be employed as shock absorbers. However, Tuti's interview suggests that women might potentially make more use of extra-household networs because of a lack of male dominance and the presence of commonalities among women, in this case, the Qur'an recitation women group and her aunt Yayan, who is also a TB survivor.

These contrasting experiences of my respondents signifies how social capital for women can serve as intermediary that heightens their vulnerability while also acting as a protective factors for women in the case of TB diagnosis. In regard to TB and household coping mechanism of intrahousehold labour substitution, these facets are oftentimes framed as indicators of 'resilience' while ignoring the apparent vulnerability experienced by women in the household.

Furthermore, this chapter suggest two key implications. Firstly, there may be a barrier preventing TB patients from reintegrating into the workforce. Additional studies on these barriers unfold may deepen our understanding of the connections between TB and persistent poverty, which may serve as a

foundation for a different, more transformative approach to social protection policies that meet the needs of both patients and their households.

Additionally, in regard to role of extra-household networks play as protective factors raise an crucial questions: what happens if the woman doesn't have any social networks outside of her home? If the woman takes on two roles during a health crisis and doesn't have adequate external assistance, what can happen to the welfare of her and her home? These questions demands more investigation.

8. Conclusion

Since the post-2015 WHO End TB era, there has been an increase in studies regarding social protection for TB. Yet many of these studies are shaped by a state-centric bias and a preference for financial remedies such as cash transfers. This limited view of social protection reflects an assessment of the disease burden of TB grounded in the productivist-oriented 'cost of illness' and human capital approach. Consequently, dominant understandings of TB burden have tended to fixate on the financial burden incurred by individuals. In reality, chronic disease such as TB renders long-term consequences which affect not only individuals but also households as a whole, especially in country such as Indonesia where there's a higher reliance towards households due to limited reach of social protection. Thus, I contend that this approach is insufficient to understand the larger impact of TB on households.

One way to gain insight into the impact of TB beyond the individual level is to conduct a baseline study that explores the livelihood dynamics of TB-affected households. In this regard, I started off this study by conceptualising informal social protection through a regime-based approach framework provided by (Mumtaz, 2022) and (Razavi, 2007). This outlook allows us to see various institutions that have a role in TB welfare ecosystem and how they operate. Following my findings, the most prominent institutions are families and non-state actors (Puskesmas and CBO), whose goal is mainly to provide immediate relief and prevent welfare losses.

After mapping institutions and roles, I narrowed down to the household level to examine the implications of the most commonly employed coping strategy, including intrahousehold labour substitution. As per to my observations, this frequently takes the shape of the woman assuming up the husband's duties as provider in the family in order to compensate for income loss or boost family income in order to fulfil additional expenses associated with TB and other household expenditure.

One lesser-known aspect of coping strategies is how people view women's vulnerability as a means to boost household resilience while in reality, this phenomenon is a consequence of women's subjugated position within kinship relationships due to male dominance. Thieme and Siegmann (2010) showed how these imbalanced power dynamics within the household enable the exploitation of women as shock absorbers, even though women themselves cannot leverage the relationships they are engaged in. This is evident in the significant shift in

the division of labour when the husband contracts TB, while it remains relatively unchanged if the woman is affected by the disease.

However, extra-household social capital can assist women in better coping with TB. Unlike intra-household dynamics, which are marked by unequal power relations due to gender norms, extra-household interactions can serve as a protective mechanism. In these external networks, there is less influence of masculine domination, and a shared identity within these networks allows women to leverage their position more effectively. This is evident through the experience of Siti which received most support from women's groups, and particularly her aunt who have shared experiences as TB survivors and mother.

Appendices

Interview guide for patients/former patients and family member

1. Can you tell me about the recovery process from TB?
2. During the treatment recovery process, what was the most challenging part? For example, side effects of medication, needs during TB (transportation, food), or others
3. What part do you think is the most expensive during the treatment recovery process?
4. Where do the costs to support your medical recovery come from, such as costs for transportation or food?
5. Can you explain the difference in financial burden after and before contracting TB?
    a. What dimensions are most affected?
    b. In what phase is the financial burden heavy?
    c. How does this affect your treatment?
6. What challenges do you face in accessing TB treatment?
    a. Access/distance
    b. Information – did you previously know about the TB program at the Puskesmas?
7. In your opinion, to what extent does TB affect the welfare of your family?
    a. To what extent are other family members affected?
8. Which part has the biggest impact? Loss of job, children's education, wife/husband has to work?
9. Have you ever received assistance or support from community organizations to support recovery from TB treatment?
    a. In what aspects does help and support help you?
        i. Emotional support
        ii. Foods
        iii. Health access
        iv. Information
        v. (stigma) Do you feel comfortable with your help to talk about your condition?
    b. Who provides the assistance?
        i. Community organization
        ii. Mosque/Churches/ other religious institution
        iii. Immediate or extended family
10. In your opinion, how does the assistance or support provided help recovery from TB treatment and the welfare of your family?
    a. Helps with medication adherence
    b. Improvement of family welfare
11. In your opinion, from your experience, how can the government help TB patients complete treatment?
12. Is there anything else you would like to share about your experience with how TB affects the well-being of you and your family?

Interview guide for CBO personnel and patient support

1. Can you tell me about your experience in accompanying TB patients? As a cadre and also as a person who advocates for TB issues
2. In your opinion, what are the roles and contributions of NGOs in supporting TB patients during their treatment journey?
3. Do NGOs provide practical assistance to TB patients? For example transportation, food?
4. How does the assistance provided help TB patients?
    a. Treatment results for TB patients
    b. Compliance with taking medication
    c. Family welfare
    d. Stigma – does the assistance provided play a role in overcoming social stigma?
5. According to you, what types of support are provided by TB cadres/NGOs to TB patients?
    a. From your experience, have you ever provided assistance outside of your work obligations?
6. What challenges or obstacles do you face in helping TB patients?
    a. How do these challenges affect your ability to help TB patients?
7. Have you, as a cadre or organization, ever collaborated with other community organizations, families of TB patients, RT/RW, Puskesmas? Do you think this collaboration can strengthen the support network for TB patients? – if Yes, How does this collaboration strengthen the support network
8. How do TB cadres or NGOs facilitate TB patient connections with other support networks?
9. How do TB cadres or NGOs facilitate the relationship between TB patients and the Puskesmas TB program?
10. Based on your personal experience, are there any suggestions or recommendations you would like to convey to the government regarding welfare support for TB patients? How is it possible for TB cadres or NGOs to collaborate with the formal health system to help TB patients?
11. Is there anything else you would like to share about your experience working with TB patients? Are there any important views or insights that you would like to convey to the government, health service providers?

Interview for health workers

1. As a health worker, how do you see your role in providing support to TB patients (and/or families) outside of medical assistance?
    a. Practical support (nutrition, money, etc.)
    b. Emotional support
2. In your experience, has the Puskesmas ever provided or been involved in providing welfare assistance to TB patients and their families?
    a. Whether or not there is social assistance for TB patients
3. In your experience, what type of welfare support is most needed by TB patients and affected families? How this support can help patients and families
4. (optional) In your experience, what are the challenges faced by Puskesmas in providing welfare/social assistance?
5. In your experience, what challenges do patients experience in being able to access treatment and comply with taking medication/complete treatment?
    a. Are there differences in the challenges faced by TB patients from different social and economic backgrounds?
    b. Can you describe the patients who are most vulnerable to dropping out?
6. Has the Puskesmas ever collaborated with other support networks such as community groups, RT/RW, companies to provide support to TB patients?
    a. What form does the collaboration take?
7. What is the role of the Puskesmas to ensure patients are connected to a support network? I
8. If, for example, there is a social assistance program, what is the role of Pukesmas in this program? Do you think the Puskesmas can play a role in this program?
    a. Puskesmas burden
    b. Additional resources for Puskesmas
9. Based on your personal experience, are there any suggestions or recommendations you would like to convey to the government regarding welfare support for TB patients?
10. Is there anything else you would like to share about your experience working with TB patients? Are there any important views or insights that you would like to convey to the government, health service providers?

References

Baig, R.B. and Chang, C. (2020) 'Formal and Informal Social Support Systems for Migrant Domestic Workers', *The American behavioral scientist (Beverly Hills),* 64(6), pp. 784-801 Available at: 10.1177/0002764220910251.

Basakha, M., Soleimanvandiazar, N., Tavangar, F. and Daneshi, S. (2021) 'Economic Value of Life in Iran: The Human Capital Approach', *Iranian journal of public health,* 50(2), pp. 384-390 Available at: 10.18502/ijph.v50i2.5357.

Behar, R. (1997) *The Vulnerable Observer.* 1st edn. New York: Beacon Press.

Berger, R. (2015) 'Now I see it, now I don't: researcher's position and reflexivity in qualitative research', *Qualitative research : QR,* 15(2), pp. 219-234 Available at: 10.1177/1468794112468475.

Bogdan, R.C. and Biklen, S.K. (1998) *Qualitative Research in Education. An Introduction to Theory and Methods. Third Edition.* Allyn & Bacon, A Viacom Company.

Claudia Rokx, John Giles, Elan Satriawan, Puti Marzoeki, Pandu Harimurti, Elif Yavuz (2010) *New Insights into the Provision of Health Services in Indonesia.* Washington, DC: World Bank.

Courtwright, A. and Turner, A.N. (2010) 'Tuberculosis and Stigmatization: Pathways and Interventions', *Public health reports (1974),* 125, pp. 34-42 Available at: 10.1177/00333549101250S407.

de Lima, M.B., Mello, D.A., Morais, A.P. and da Silva, W.C. (2001) 'Non-adherence to tuberculosis treatment: a study on perceptions and knowledge of the disease and evaluation of health services from the patient perspective', *Cadernos de saúde pública,* 17(4), pp. 877-885.

DeSanto, D., Velen, K., Lessells, R., Makgopa, S., Gumede, D., Fielding, K., Grant, A.D., Charalambous, S. and Chetty-Makkan, C.M. (2023) 'A qualitative exploration into the presence of TB stigmatization across three districts in South Africa', *BMC public health,* 23(1), pp. 504 Available at: 10.1186/s12889-023-15407-2.

Emerson, R.M., Fretz, R.I. and Shaw, L.L. (2011) 'Processing Fieldnotes: Coding and Memoing'*Writing Ethnographic Fieldnotes* United States: University of Chicago Press, pp. 172-199.

European Parliament (2013) *DIRECTORATE-GENERAL FOR EXTERNAL POLICIES OF THE UNION DIRECTORATE B POLICY DEPARTMENT BRIEFING "FEASIBILITY OF SOCIAL PROTECTION SCHEMES IN DEVELOPING COUNTRIES"*, Belgium: European Parliament.

Farmer, P. (1997) 'Social scientists and the new tuberculosis', *Social science & medicine (1982),* 44(3), pp. 347-358 Available at: 10.1016/S0277-9536(96)00143-8.

FOA (2023) *Gendered Resilience to Shock and Stresses* . Available at: https://www.fao.org/3/cc5343en/online/status-women-agrifood-systems-2023/gendered-resilience-shocks-stresses.html#note-5_4 (Accessed: 6 November 2023).

Freitas, I.M., Crispim, J.d.A., Pinto, I.C., Villa, T.C.S., Brunello, M.E.F., Pinto, P.F.P.S. and Arcêncio, R.A. (2012) 'Conhecimento e percepção sobre tuberculose das famílias de pacientes em tratamento diretamente observado em um serviço de saúde de Ribeirão Preto-SP, Brasil', *Texto & contexto enfermagem,* 21(3), pp. 642-649 Available at: 10.1590/S0104-07072012000300020.

Fuady, A., Houweling, T.A.J., Mansyur, M., Burhan, E. and Richardus, J.H. (2020a) 'Cost of seeking care for tuberculosis since the implementation of universal health coverage in Indonesia', *BMC health services research,* 20(1), pp. 502 Available at: 10.1186/s12913-020-05350-y.

Fuady, A., Houweling, T.A.J., Mansyur, M., Burhan, E. and Richardus, J.H. (2020b) 'Cost of seeking care for tuberculosis since the implementation of universal health coverage in Indonesia', *BMC health services research,* 20(1), pp. 502 Available at: 10.1186/s12913-020-05350-y.

Fuady, A., Houweling, T.A.J., Mansyur, M. and Richardus, J.H. (2018a) 'Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of universal health coverage', *Infectious Diseases of Poverty,* 7(1), pp. 3 Available at: 10.1186/s40249-017-0382-3.

Fuady, A., Houweling, T., Mansyur, M. and Richardus, J.h. (2018b) 'Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of universal health coverage', *Infectious Diseases of Poverty,* 7(1), pp. 3 Available at: 10.1186/s40249-017-0382-3.

Goudge, J., Russell, S., Gilson, L., Gumede, T., Tollman, S. and Mills, A. (2009) 'ILLNESS-RELATED IMPOVERISHMENT IN RURAL SOUTH AFRICA: WHY DOES SOCIAL PROTECTION WORK FOR SOME HOUSEHOLDS BUT NOT OTHERS? ', *Journal of international development,* 21(2), pp. 231-251 Available at: 10.1002/jid.1550.

Gough, I. (2004) 'Welfare regimes in development contexts: A global and regional analysis'*Insecurity and Welfare Regimes in Asia, Africa and Latin America: Social Policy in Development Contexts*.

Hafez, R., Harimurti, P. and Martin-Hughes, R. (2020) *Tuberculosis in Indonesia : Epidemic Projections and Opportunities to Accelerate Control.* World Bank, Washington, DC. Available at: http://hdl.handle.net/10986/35370 (Accessed: .

Ho, J., Byrne, A.L., Linh, N.N., Jaramillo, E. and Fox, G.J. (2017) 'Decentralized care for multidrug-resistant tuberculosis: a systematic review and meta-analysis', *Bulletin of the World Health Organization,* 95(8), pp. 584-593 Available at: 10.2471/BLT.17.193375.

Inayah, S. and Wahyono, B. (2019) 'Penanggulangan Tuberkulosis Paru dengan Strategi DOTS', *Journal of Public Health Research and Development,* 3(2), pp. 223-233 Available at: https://doi.org/10.15294/higeia.v3i2.25499.

Jackson, S., Sleigh, A.C., Wang, G. and Liu, X. (2006) 'Poverty and the economic effects of TB in rural China', *The international journal of tuberculosis and lung disease,* 10(10), pp. 1104-1110.

Karumbi, J., Garner, P. and Karumbi, J. (2015) 'Directly observed therapy for treating tuberculosis', *Cochrane database of systematic reviews,* 2015(5), pp. CD003343 Available at: 10.1002/14651858.CD003343.pub4.

Kemenkes, R.I. (2022) *Program Penanggulangan Tuberkulosis*. Jakarta: Kementerian Kesehatan Republik Indonesia. Available at: https://tbindonesia.or.id/wp-content/uploads/2023/09/Laporan-Tahunan-Program-TBC-2022.pdf (Accessed: .

Kementerian Kesehatan Republik Indonesia (2020a) *Petunjuk Teknis Penatalaksanaan Tuberkulosis Resistent Obat di Indonesia*, Jakarta: Kementerian Kesehatan Republik Indonesia.

Kementerian Kesehatan Republik Indonesia (2020b) *Strategi Nasional Penanggulangan Tuberkulosis di Indonesia 2020-2024*, Jakarta: Kementerian Kesehatan Republik Indonesia.

Peraturan Menteri Kesehatan Nomor 67 Tahun 2016 tentang Penanggulangan Tuberkulosis (SI year and number). Available at: https://peraturan.bpk.go.id/Details/114486/permenkes-no-67-tahun-2016 (Accessed: .

Kristiansen, S. and Santoso, P. (2006) 'Surviving decentralisation? Impacts of regional autonomy on health service provision in Indonesia', *Health policy (Amsterdam),* 77(3), pp. 247-259 Available at: 10.1016/j.healthpol.2005.07.013.

Ku, C., Chen, C., Dixon, S., Lin, H.H. and Dodd, P.J. (2020) 'Patient pathways of tuberculosis care-seeking and treatment: an individual-level analysis of National Health Insurance data in Taiwan', *BMJ global health,* 5(6), pp. e002187 Available at: 10.1136/bmjgh-2019-002187.

Lestari, B.W., McAllister, S., Hadisoemarto, P.F., Afifah, N., Jani, I.D., Murray, M., van Crevel, R., Hill, P.C. and Alisjahbana, B. (2020) 'Patient pathways and delays to diagnosis and treatment of tuberculosis in an urban setting in Indonesia', *The Lancet regional health. Western Pacific,* 5, pp. 100059 Available at: 10.1016/j.lanwpc.2020.100059.

Liu, Y., Xu, C., Wang, X., Wang, Z., Wang, Y., Zhang, H. and Wang, L. (2020) 'Out-of-pocket payments and economic consequences from tuberculosis care in eastern China: income inequality', *Infectious Diseases of Poverty,* 9(1), pp. 14 Available at: 10.1186/s40249-020-0623-8.

Mahendradhata, Y., Syahrizal, B.M. and Utarini, A. (2008) 'Delayed treatment of tuberculosis patients in rural areas of Yogyakarta province, Indonesia', *BMC Public Health,* 8(1), pp. 393 Available at: 10.1186/1471-2458-8-393.

McAllister, S.M., Wiem Lestari, B., Sullivan, T., Fortuna Hadisoemarto, P., Afifah, N., Arosdiani Apip, R., Murray, M., Hill, P.C. and Alisjahbana, B. (2020a) 'Out-of-Pocket Costs for Patients Diagnosed with Tuberculosis in Different Healthcare Settings in Bandung, Indonesia', *The American journal of tropical medicine and hygiene,* 103(3), pp. 1057-1064 Available at: 10.4269/ajtmh.19-0848.

McAllister, S.M., Wiem Lestari, B., Sullivan, T., Fortuna Hadisoemarto, P., Afifah, N., Arosdiani Apip, R., Murray, M., Hill, P.C. and Alisjahbana, B. (2020b) 'Out-of-Pocket Costs for Patients Diagnosed with Tuberculosis in Different Healthcare Settings in Bandung,

Indonesia', *The American journal of tropical medicine and hygiene,* 103(3), pp. 1057-1064 Available at: 10.4269/ajtmh.19-0848.

Meghji, J., Gregorius, S., Madan, J., Chitimbe, F., Thomson, R., Rylance, J., Banda, N.P., Gordon, S.B., Corbett, E.L., Mortimer, K. and Squire, S.B. (2021) 'The long term effect of pulmonary tuberculosis on income and employment in a low income, urban setting', *Thorax,* 76(4), pp. 387-395 Available at: 10.1136/thoraxjnl-2020-215338.

Mokomane, Z. (2013) 'Social protection as a mechanism for family protection in sub-Saharan Africa', *International journal of social welfare,* 22(3), pp. 248-259 Available at: 10.1111/j.1468-2397.2012.00893.x.

Moreira, A.d.S.R., Kritski, A.L. and Carvalho, A.C.C. (2020) 'Social determinants of health and catastrophic costs associated with the diagnosis and treatment of tuberculosis', *Jornal brasileiro de pneumologia,* 46(5), pp. e20200015 Available at: 10.36416/1806-3756/e20200015.

Motel-Klingebiel, A., Tesch-Roemer, C. and Von Kondratowitz, H. (2005) 'Welfare states do not crowd out the family: evidence for mixed responsibility from comparative analyses', *Ageing and society,* 25(6), pp. 863-882 Available at: 10.1017/S0144686X05003971.

Mumtaz, Z. (2022) 'Informal social protection: A conceptual synthesis', *Social policy & administration,* 56(3), pp. 394-408 Available at: 10.1111/spol.12772.

Munro, S.A., Lewin, S.A., Smith, H.J., Engel, M.E., Fretheim, A. and Volmink, J. (2007) 'Patient Adherence to Tuberculosis Treatment: A Systematic Review of Qualitative Research', *PLoS Medicine,* 4(7), pp. e238 Available at: 10.1371/journal.pmed.0040238.

Noerfitri, N., Sutiawan, R., Wahyono, T.Y.M. and Hartono, P.A. (2019) 'Influence of Decentralization and Type of patient on Lost to follow-up in Multidrug-Resistant Tuberculosis Patients in Indonesia 2014-2015: A Survival Analysis', *Kesmas (Depok),* 13(3) Available at: 10.21109/kesmas.v13i3.2710.

Oduro, A. (2010) *Adverse Shocks and Social Protection in Africa: What Role for Formal and Informal Financial Institutions?*

Oliosi, J.G.N., Reis-Santos, B., Locatelli, R.L., Sales, C.M.M., da Silva Filho, W.G., da Silva, K.C., Sanchez, M.N., de Andrade, K.V.F., de Araújo, G.S., Shete, P.B., Pereira, S.M., Riley, L.W., Lienhardt, C. and Maciel, E.L.N. (2019) 'Effect of the Bolsa Familia Programme on the outcome of tuberculosis treatment: a prospective cohort study', *The Lancet global health,* 7(2), pp. e219-e226 Available at: 10.1016/S2214-109X(18)30478-9.

Paskaria, C., Sunjaya, D.K., Parwati, I. and Bestari, M.B. (2022) 'Digital Health to Strengthen District-Based Public-Private Mix Tuberculosis Control in Purwakarta District, Indonesia: A Qualitative Research', *International journal of environmental research and public health,* 19(19), pp. 12097 Available at: 10.3390/ijerph191912097.

Peng, I. (2019) *The Care Economy: a new research framework*. Laboratoire interdisciplinaire d'évaluation des politiques publiques. Available at: https://spire.sciencespo.fr/hdl:/2441/4jkd2n5qb584g97mecfn4jjvjn

Portes, A. (1998) 'Social capital: Its origins and applications in modern sociology', *Annual review of sociology,* 24, pp. 0_12.

Pradhan, A., Koirala, P., Bhandari, S.S., Dutta, S., García-Grau, P., Sampath, H. and Sharma, I. (2022) 'Internalized and Perceived Stigma and Depression in Pulmonary Tuberculosis: Do They Explain the Relationship Between Drug Sensitivity Status and Adherence?', *Frontiers in psychiatry,* 13, pp. 869647 Available at: 10.3389/fpsyt.2022.869647.

Puspita, K.A., Yanti, Z., Putri, N.K., Supriyanto, S. and Atiqah, N. (2019) 'REDESIGNING THE ROLES OF TUBERCULOSIS TREATMENT SUPPORTER IN INDONESIA', *Jurnal Administrasi Kesehatan Indonesia,* 7(2), pp. 170-177 Available at: 10.20473/jaki.v7i2.2019.170-177.

Rakmawati, T., Hinchcliff, R. and Pardosi, J.F. (2019) 'District-level impacts of health system decentralization in Indonesia: A systematic review', *The International journal of health planning and management,* 34(2), pp. e1026-e1053 Available at: 10.1002/hpm.2768.

Razavi, S. (2007) *The Political and Social Economy of Care in a Development Context: conceptual Issues, research questions and policy options.* United Nations Research Institute for Social Development.

Renjith, V., Yesodharan, R., Noronha, J., Ladd, E. and George, A. (2021) 'Qualitative methods in health care research', *International journal of preventive medicine,* 12(1), pp. 20 Available at: 10.4103/ijpvm.IJPVM_321_19.

Rice, D.P., Hodgson, T.A. and Kopstein, A.N. (1985) 'The economic costs of illness: a replication and update', *Health Care Financing Review,* 7(1), pp. 61-80.

Rice, D.P. (2000) 'Cost of illness studies: what is good about them?', *Injury prevention,* 6(3), pp. 177-179 Available at: 10.1136/ip.6.3.177.

Rintiswati, N., Mahendradhata, Y., Suharna, Susilawati, Purwanta, Subronto, Y., Varkevisser, C.M. and van der Werf, M.J. (2009) 'Journeys to tuberculosis treatment: a qualitative study of patients, families and communities in Jogjakarta, Indonesia', *BMC Public Health,* 9(1), pp. 158 Available at: 10.1186/1471-2458-9-158.

Rubinstein, F. and Blumenfeld, A. (2023) *Conditional Cash Transfer to Improve TB Outcomes: Necessary but Not Sufficient Comment on "Does Direct Benefit Transfer Improve Outcomes Among People With Tuberculosis? – A Mixed-Methods Study on the Need for a Review of the Cash Transfer Policy in India"* Maad Rayan Publishing Company.

Russell, S. (1996) 'Ability to pay for health care: concepts and evidence', *Health policy and planning,* 11(3), pp. 219-237 Available at: 10.1093/heapol/11.3.219.

Sauerborn, R., Adams, A. and Hien, M. (1996a) 'Household strategies to cope with the economic costs of illness', *Social science & medicine (1982),* 43(3), pp. 291-301 Available at: 10.1016/0277-9536(95)00375-4.

Sauerborn, R., Adams, A. and Hien, M. (1996b) 'Household strategies to cope with the economic costs of illness', *Social science & medicine (1982),* 43(3), pp. 291-301 Available at: 10.1016/0277-9536(95)00375-4.

Smith, A., Herington, E. and Loshak, H. (2021) 'Tuberculosis Stigma and Racism, Colonialism, and Migration: A Rapid Qualitative Review', *Canadian Journal of Health Technologies,* 1(4) Available at: 10.51731/cjht.2021.56.

Steffen, R., Menzies, D., Oxlade, O., Pinto, M., de Castro, A.Z., Monteiro, P. and Trajman, A. (2010) 'Patients' Costs and Cost-Effectiveness of Tuberculosis Treatment in DOTS and Non-DOTS Facilities in Rio de Janeiro, Brazil', *PLoS ONE,* 5(11), pp. e14014 Available at: 10.1371/journal.pone.0014014.

Tansey, O. (2007) 'Process Tracing and Elite Interviewing: A Case for Non-probability Sampling', *PS, political science & politics,* 40(4), pp. 765-772 Available at: 10.1017/S1049096507071211.

Thieme, S. and Siegmann, K.A. (2010) 'Coping on Women's Backs', *Current sociology,* 58(5), pp. 715-737 Available at: 10.1177/0011392110372732.

Todd, H., Hudson, M., Grolmusova, N., Kazibwe, J., Pearman, J., Skender, K., Tran, P.B., Boccia, D., Shete, P.B. and Wingfield, T. (2023) 'Social Protection Interventions for TB-Affected Households: A Scoping Review', *The American journal of tropical medicine and hygiene,* 108(4), pp. 650-659 Available at: 10.4269/ajtmh.22-0470.

Turusbekova, N., Celan, C., Caraulan, L., Rucsineanu, O., Jibuti, M., Ibragimova, O. and Saidova, N. (2022) 'Gender-related factors associated with delayed diagnosis of tuberculosis in Eastern Europe and Central Asia', *BMC public health,* 22(1), pp. 1-1999 Available at: 10.1186/s12889-022-14419-8.

Ukwaja, K.N., Alobu, I., Lgwenyi, C. and Hopewell, P.C. (2013) 'The High Cost of Free Tuberculosis Services: Patient and Household Costs Associated with Tuberculosis Care in Ebonyi State, Nigeria', *PLoS ONE,* 8(8), pp. e73134 Available at: 10.1371/journal.pone.0073134.

WHO (2023) *Tuberculosis.* Available at: https://www.who.int/news-room/fact-sheets/detail/tuberculosis (Accessed: 9 November 2023).

WHO (2022) *The TB Joint External Monitoring Mission (JEMM)* , Jakarta: World Health Organization.

WHO (2015) *WHO Global TB Programme Protocol for survey to determine direct and indirect costs due to TB and to estimate proportion of TB-affected households experiencing catastrophic costs (November 2015) Protocol for survey to determine direct and indirect costs due to TB and to estimate proportion of TB-affected households experiencing catastrophic total costs due to TB Field testing version World Health Organization, Global TB Programme* WHO.

WHO (2009) *A brief history of tuberculosis control in Indonesia* World Health Organization.

Wingfield, T., Tovar, M.A., Huff, D., Boccia, D., Saunders, M.J., Datta, S., Montoya, R., Ramos, E., Lewis, J.J., Gilman, R.H. and Evans, C. (2016) 'Beyond pills and tests: addressing the social determinants of tuberculosis', *Clinical medicine (London, England),* 16(Suppl 6), pp. s79-s91 Available at: 10.7861/clinmedicine.16-6-s79.

Wood, G. and Gough, I. (2006) 'A Comparative Welfare Regime Approach to Global Social Policy', *World Development,* 34(10) Available at: 10.1016/j.worlddev.2006.02.001.

World Bank (2023) *The World Bank In Social Protection.* Available at: https://www.worldbank.org/en/topic/socialprotection/overview (Accessed: 13 October 2023).

World Bank (2005) *East Asia decentralizes : making local government work.* Washington, D.C: World Bank.

Zawedde-Muyanja, S., Reuter, A., Tovar, M.A., Hussain, H., Loando Mboyo, A., Detjen, A.K. and Yuen, C.M. (2021) 'Provision of Decentralized TB Care Services: A Detect–Treat–Prevent Strategy for Children and Adolescents Affected by TB', *Pathogens (Basel),* 10(12), pp. 1568 Available at: 10.3390/pathogens10121568.