Social Security for People Affected by Drug-Resistant TB

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Keywords: Social Security, Drug Resistance TB.

Abstract: The high incidence of Drug Resistance Tuberculosis (DR TB) and the low number of people with DR TB who get treatment shows that the prevention of DR TB in Indonesia requires serious attention. Need about 24 months for treatment and healing and requires huge financing and adherence. Although the government has facilitated treatment for people affected by DR TB through National Health Insurance (JKN), and enabler support from the TB Control program funded by the Global Fund, however not all people with DR TB received that assistance. This study focuses on examining the importance of social security for people with DR TB and analyzing the adequacy of policies so that social security can be implemented for people with DR TB. This study finds that DR TB is a catastrophic disease that brings about poverty to patients with multi-dimension impacts including physiological, psychological, social, and economic. The integration of DR TB into social security is feasible in Indonesia. Finally, this study looks at the issuance of Presidential Decree No. 67 in the year 2021 about TB control becoming a very strong base for the integration of TB-affected people into social protection programs.

1 INTRODUCTION

Currently, Indonesia is ranked third in the world with the most TB cases in the world after India and China. According to the Global TB Report 2021 data, the estimated TB cases in Indonesia are 824,000, but notifications currently only reach 443,235 (53.79%) cases per year. Of the number that was notified, 8,268 (1.86%) of them confirmed TBC RO.

The spread of TB RO is a challenge, the data on the Indonesian TB enrollment rate or the number of people starting TB treatment for TB is only around 45%. There are still around 55% (1,819) of people with TB RO who do not get treatment and have the potential to infect others around them (Ministry of Health, 2022).

The government has borne the direct medical costs of TB RO treatment (direct medical costs) through the National Health Insurance (JKN). However, in practice in certain conditions and areas, people with RO TB need to spend money on other costs such as radiology, laboratory tests, and anti-TB RO drugs (if they are found to be out of stock at the health facilities). In addition, people affected by TB RO currently receive enabler fees, from the TB control program funded by the Global Fund, to address direct non-medical costs such as transportation costs. However, in its implementation, not everyone affected by TB RO has received this enabler fund (STPI, 2022).

Likewise, some people affected by TB RO have also received social security schemes such as PKH (Program Keluarga Harapan), Basic Food Assistance, assistance from local governments, and others. However, the allocation of the social security scheme is not specific, partial, and incidental (the scheme is not clear), and only considers the condition of poverty. Therefore, the government needs to provide social security for people affected by TB RO by

Annisa, N., Rais, A., Alief, D., Kurniawan, D., Gunawan, U., Laksono, I. and Nurlianti, .
Social Security for People Affected by Drug-Resistant TB.
DOI: 10.5220/0011662200003608
In *Proceedings of the 4th International Conference on Social Determinants of Health (ICSDH 2022)*, pages 180-185
ISBN: 978-989-758-621-7; ISSN: 2975-8297
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compiling rules and mechanisms as well as better monitored implementation. One of the social security programs for people with TB RO is the CCT model; namely a conditional cash transfer program aimed at poor households, by requiring these households to make long-term investments in Human Resources (HR) such as improving education, health, and improving nutrition. This program is noted as an important component of social protection systems and poverty reduction in many countries, especially developing countries (World Bank, 2009). The CCT model is considered relevant in TB RO to help TB RO patients increase family income to prevent catastrophic costs. In addition, because the CCT approach requires conditionality adherence to treatment for TB RO patients can be monitored.

Previous research conducted by Fuady (2018), Estro (2021), and WHO (2022) showed catastrophic costs faced by TB RO sufferers. However, there is a research gap in aspects that analyze the condition of people affected by TB RO, available social security policies, and the urgency of implementing social security. Based on these things, STPI conducted a study on Social Security for People Affected by TB RO which aims to see a description of the condition of people affected by TB RO including the needs and constraints experienced, as well as analyzing policy opportunities that exist in Indonesia regarding the urgency of social security for affected people. TB RO. With the presence of policies that are more supportive of TB RO, it is hoped that the recovery of people affected by TB RO will increase to achieve TB elimination in Indonesia.

2 METHODOLOGIES

This research was conducted using a mixed method with a convergent parallel design (that is, the use of quantitative and qualitative research at the same time or phase) to answer the formulation of the research problem. The methods used include literature review, surveys, interviews with people with TB RO and TBC RO stakeholders both from government agencies and CSOs, FGDs with TB stakeholders from government agencies and CSOs, policy analysis, and mapping of key stakeholders.

Sampling in the survey was determined by the purposive sampling method with criteria for people affected by TB RO who had started second-line treatment and were in 10 areas (North Sumatra, South Sumatra, Lampung, DKI Jakarta, Banten, West Java, Central Java, DI Yogyakarta, East Java, and South Sulawesi) assisted by PR of the STPI Penabulu Community Consortium. The survey was conducted by Case Managers as enumerators of 332 people with TB RO which was conducted in the period December 2021 to February 2022.

3 DISCUSSIONS

3.1 Multidimensional Impact on People with TB RO

Physical impact. People with TB RO who undergo treatment for 9-20 months with a very large number of treatment regimens will experience several side effects, such as dizziness/headache, chest pain, diarrhea, muscle and bone pain, nausea to vomiting, and tingling (Ministry of Health, 2020).). All these side effects then have implications for suffering and a sense of helplessness that is inevitable for patients (STPI, 2022).

Psychological impacts for people with TB RO include excessive anxiety, stress, and even depression. In some cases, people with TB RO experience hallucinations and attempt suicide (Ministry of Health, 2020). Social impact. Exclusion from family and environment and even being expelled from work or quitting school is not uncommon for them to experience (Morris, 2013). People with TB RO often get stigma internal (feeling inferior) and external (other people). Not infrequently, external stigma also comes from health workers (STPI, 2022).

Table 1: Income Levels and Respondents' Status by Participation in PKH.

Income Level	**Status in PKH Program**		
	Not Participant	**Participant**	**Total**
<Rp 500K	53 (16%)	18 (5%)	71 (21%)
Rp 500K – 1M	22 (7%)	16 (5%)	38 (11%)
Rp 1 – 2M	52 (16%)	21 (6%)	73 (22%)
Rp 2 – 3M	65 (20%)	13 (4%)	78 (23%)
Rp 3 – 4M	30 (9%)	5 (2%)	35 (11%)
Rp 4 – 5M	23 (7%)	2 (1%)	25 (8%)
> Rp 5M	12 (4%)	0 (0%)	12 (4%)
Total	**257 (77%)**	**75 (23%)**	**332 (100%)**

K=thousands, M=Million

Financial impact. For the sake of recovery treatment, it is not uncommon for people with TB RO to have to

bear direct non-medical costs such as transportation costs and consumption during treatment; indirect costs, namely the loss of productive time which results in income loss (Ahmad, et al. 2021). Compared to the needs of people with TB RO, the assistance received are still Limited.

The STPI study found that most of the respondents were poor families with an income of fewer than 2 million rupiahs (54%) and vulnerable poor families with an income below 3 million rupiahs (23%).

In terms of household expenditure, STPI's research also found that 79% of household respondents affected by TB RO bear expenses that exceed their monthly income where the average household expenditure is between 1-4 million per month with four family members.

This high expenditure creates a catastrophic burden on the families of people with TB RO. Table of Income Levels and Respondents' Status by Participation in PKH.

Another study by Estro et.al (2021) showed that 81% of people affected by TB RO experienced catastrophic discharge. The largest proportion of expenses for people with TB RO are indirect costs or lost income/jobs (60.23%), followed by non-medical costs (39.42%) and the lowest is medical costs (0.35%).

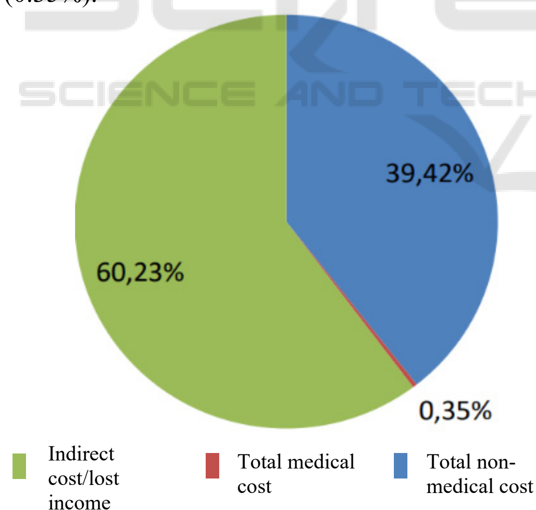

Figure 1: The proportion of total medical expenses, non-medical costs, and indirect costs

STPI's research also found that several social security mechanisms have been received by people with TB RO, including assistance for treatment and living expenses with different schemes.

Most of these aids were provided through government channels. However, this social security assistance is still provided with various, uneven and non-specific frequencies targeting people affected by TB RO. One of them, from the STPI study, showed that only 23% of TB RO respondents received the PKH program, whereas 77% of respondents earned less than 3 million rupiahs (STPI, 2022). Even 21% of them live with an income of less than 500 thousand per month. Many respondents are eligible to receive assistance from the PKH program but are not served by this program.

This situation shows that the provision of social assistance for people affected by TB RO is still based on poverty data, not their health status. People affected by TB RO have a vulnerability to being poor due to the catastrophic conditions they experience. Thus, the scope of providing social support received by TB RO patients is very limited.

3.2 Existing Social Security Has Not Specifically Targeted People Affected by TB RO Even Though the Policy Basis Already Exists

3.2.1 Title

Of the government's social security programs that have the potential to support the needs and success of treatment for TB RO patients, none specifically targets people affected by TB RO as recipients. Until now, the government has at least 25 social security programs, with 5 programs that have the potential to support the fulfillment of the treatment needs of people affected by TB RO. Social security programs that have the potential to support TB RO patients are the Healthy Indonesia Program (Healthy Indonesia Card/BPJS Kesehatan), PKH, the Basic Food Program, the Social Entrepreneurship Program (ProKus), and the Social Rehabilitation of Uninhabitable Homes (RS-RTLH).

People affected by TB were once a health component in the Family Hope Program at the end of 2020 based on the Decree of the Director General of Social Protection and Security, Ministry of Social Affairs. However, the policy was later discontinued due to the lack of a strong legal basis and studies for its implementation.

Based on the National TB Elimination Strategy, the integration of programs to support people affected by TB should be a concern because it encourages the strengthening of commitment and leadership at all levels of government through the provision of adequate budgets for TB control (Article 5 paragraph 2 (a) and Article 7 point b). The Central Government, Regional Government, and non-government are also

asked to ensure the mitigation of psychological, social, and economic support for the continuation of treatment until completion [Article 12 paragraph 8(b)], one of which is by providing health insurance and social protection [Article 24 Paragraph 3 (a))].

Further Presidential Regulation No. 67 of 2021 concerning the Prevention of Tuberculosis is an opportunity and momentum to encourage the provision of social security for people with TB RO. As stated in Chapter IV Article 24 Paragraph 1 it is stated that in the implementation of TB control, the Central Government is responsible for mitigating the psychosocial and economic impacts faced by people affected by TB and their families (point d) and carrying out social protection and empowerment efforts for people affected by TB and the community. affected by tuberculosis (point e).

The Roadmap for the Elimination of Tuberculosis in Indonesia 2020-2030 by the Ministry of Health targets a reduction in the incidence of TB by 2030 using 6 strategies and interventions. Specifically, by optimizing the supporting procedures for the diagnosis and treatment of Drug Sensitive Tuberculosis (TB SO) and TB RO in an integrated manner by increasing psychosocial and economic support for people affected by tuberculosis, including ensuring justice in work (at point 2.3) and strengthening the financing system for tuberculosis (point 2). 6.3). The strategies and policies above clearly support the availability of social security for people with TB RO.

3.3 Lack of Synergy between Ministries and Institutions in Combating TB RO and Integration of Social Security

The government's initiative to provide social security for people affected by TB RO is still constrained. In the regulatory aspect, there is no specific nomenclature for people affected by TB RO as beneficiaries of social security. In the context of its application, social security for people with TB RO requires complex data integration.

Judging from the opportunities, synergies across key ministries (Ministry of Health and Ministry of Social Affairs) for social security for people affected by TB RO are already open. From the aspect of data availability, at least each of these ministries already has a database (SITB/Tuberculosis Information System and DTKS/Social Welfare Integrated Data) so they only need to integrate and regulate technical matters and management mechanisms. From the aspect of the regulatory base for synergies between ministries and institutions in TB control, there has also been legal strengthening, namely Presidential Regulation no. 67 of 2021 concerning the Prevention of Tuberculosis. Even in the Presidential Regulation, it has also been mandated to both central and regional governments to mitigate the psychosocial and economic impacts faced by TB patients and their families.

In addition, the National Tuberculosis Strategy document 2020-2024 states that one of the interventions that need to be carried out is multi-stakeholder and cross-program collaboration to increase the number of people with TB RO who start treatment, including through financial protection for people affected by TB by integrating psychosocial and social security systems. the economy of people affected by TB RO into protection schemes in other ministries such as programs at the Ministry of Social Affairs.

3.4 CCT as a Social Security Model for People Affected by TB RO

The provision of social security is a solution to mitigate the psychosocial and economic burdens that must be borne by people affected by TB RO and their families. A modeling analysis conducted by Carter (2018), shows that the global incidence of TB will decrease by 84.3% if poverty is eliminated and all individuals are enrolled in social protection programs, while if only social protection is applied, TB cases will decrease by 76.1%. Oliosi (2019) concluded that TB patients who are integrated into the social security or protection system have an 88% greater chance of recovering compared to TB patients who do not have a social security program.

Several countries have succeeded in reducing the catastrophic burden as well as having a positive impact on reducing TB morbidity through policies and implementation of providing social security for people with TB RO. Among these countries are Brazil, India, Argentina, and South Africa. The model of providing social security for people with tuberculosis that has been implemented in these countries is based on CCT, namely a conditional cash transfer program. CCT beneficiaries are bound by an agreement made together to support the smooth process of treatment until recovery. Indonesia adopted a CCT-based social security program in 2007 namely PKH. PKH participants or recipients are eligible, that is, they are categorized as poor and vulnerable families. The program is also an entry point for other social assistance programs for beneficiary families. However, the drawback of PKH is that it is distributed every three months, and is

considered quite long by people with TB RO. Therefore, the application of social security support to people affected by TB RO is very important considering the duration of the distribution of aid.

4 CONCLUSIONS

From the studies that have been conducted, it can be concluded that:

- Drug-resistant TB is a disease with a multi-dimensional impact and has a catastrophic cost.
- The support needed by people affected by TB RO consists of medical support, non-medical support, and indirect costs.
- The policy basis for the implementation of social security support for people affected by TB RO already exists, namely Presidential Regulation No. 67 the year 2021
- The challenge lies in lowering policy and implementation because it involves cross-Ministry/Agency

The model of providing support can be in the form of Conditional Cash Transfer (CCT) because it is proven to be able to anticipate poverty while increasing the recovery of TB patients.

5 RECOMMENDATIONS

By understanding and exploring the importance of comprehensive support and assistance for TBC RO, seeing the existence of policy gaps on the one hand and on the other hand opening up policy opportunities to fulfill the needs of TBC RO. Several things are recommended from this study to fill opportunities for the creation of better policy spaces and research developments in the future, this study recommends the following:

5.1 Recommendations for the Government

(1) It is urgent to develop a policy that provides social security support for people affected by TB RO. Considering that TB RO is a condition that impoverishes the economy of the affected people and their families, and reduces the productivity and quality of society and the nation at large. The treatment period for TB RO is 24 months, which is a very difficult challenge both in terms of time and the side effects of the drugs experienced. The impact is felt both by people with TB RO and their families. With the integration of social security for people affected by TB RO, it is hoped that they will be able to ease their socio-economic burden, support assistance and supervision of treatment to complete and recover, change the behavior of people affected by TB RO to be healthier until the 2030 TB elimination target is achieved.

(2) Policies that will come later can be following needs and strategies based on their conditionality and TB elimination targets.

(3) Supporting the government to integrate people affected by TB RO as one of the recipients of the Family Hope Program (PKH) as a relevant and appropriate CCT-based social security program to support the treatment process until they recover.

(4) Encouraging the government to immediately follow up Presidential Regulation No. 67 of 2021 concerning TB Control into the Technical Guidelines/Juknis so that it can be immediately used by Ministries, Institutions, and local governments.

(5) The policy on social security for people affected by TB RO can be in the form of a Joint Regulation of the Minister of Social Affairs and the Minister of Health or a Regulation of the Coordinating Ministry for Human Development and Culture.

5.2 Recommendations for the Academics

(1) Encouraging studies and research, evaluation, and learning on social security and protection programs that have been carried out by the government, both in terms of effectiveness, the efficiency of governance, as well as the impact on target groups and accountability and accountability.

(2) Increase research on social security that covers the needs and protection of people affected by TB.

(3) Encourage studies related to social protection and social welfare with a comprehensive approach.

ACKNOWLEDGEMENTS

Thank you to Stop TB Partnership Indonesia for supporting this study.

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