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Perceived Burden of Multidrugs- Resistant Tuberculosis Patients And Their Family: A Systematic Review Of The Qualitative Literature

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Abstract--- *The incidence of Multiple Drugs Resistance Tuberculosis (MDR TB) is still very high. MDR TB treatments require a long period of care that could lead to an impact on MDR TB patients and their families. This study aims at reviewing and synthesizing the perceived burden of MDR TB patients and their families. A literature review was conducted through a search of four journal databases which found eight articles according to the inclusion criteria which were then identified, evaluated and synthesized. A thematic synthesis was conducted of the selected studies. This review identified four major themes related to the perceived burden by MDR TB patients and their family, namely; physical, psychological, social and financial burden. Understanding the difficulties and burdens experienced by MDR TB patients and their families is important in order to choose the appropriate intervention according to the problems that may arise due to MDR TB disease.*

Keywords--- *Family; Multiple Drugs Resistance Tuberculosis; Perceived Burden; Systematic Review*

I. INTRODUCTION

TB MDR (Tuberculosis Multi Drugs Resistants) are TB patients who experience resistance to TB drugs, especially Isoniazid and Rifampicin together. MDR TB is a global health problem. The World Health Organization states that, among the new cases of TB sufferers, 4.1% of cases are estimated to have MDR TB [1]. In 2013, the World Health Organization estimated that there were 8.6 million TB cases in 2012 with 1.1 million people (13%) being HIV positive, and 450 thousand people suffering from MDR TB.

Data from the Ministry of Health of Indonesia state that there is an increasing trend in the discovery of MDR TB cases at the national level from year to year [2]. WHO 2015 data states that Indonesia is ranked 8th out of 27 countries that have the highest burden of MDR TB in the world with an estimated 6,800 new cases of MDR TB each year.

TB treatment requires a long period of time (approximately 6-8 months) to achieve cure with several drugs. The rate of TB patient adherence to treatment is estimated to be around 40% in developing countries. This is still the main cause of treatment failure globally [3]. Failure of treatment in TB sufferers will risk becoming MDR TB.

MDR TB is caused by tuberculosis bacterial resistance to antimicrobial drugs used to treat TB [4]. There are several factors that contribute in MDR-TB; inadequate use of anti-tuberculosis drugs, formulations of ineffective use

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of drugs (for example, the use of only one type of drug, poor quality drugs or poor storage of drugs), and non-compliance of anti-TB drugs consumptions which can cause drug resistance [4], [5].

Management of MDR TB patients is more complex compared to treatment of TB patients. Drug options for managing MDR TB are very limited and expensive. Drugs recommended for treating MDR TB are not always available in healthcare facilities and TB sufferers experience many side effects from taking TB drugs. In addition to the difficulty of getting drugs for MDR TB, the method of administration through drug injection is less effective than the first line; patients with MDR TB also require longer treatment time and also require more costs. The time needed for the treatment of MDR TB is approximately two years or more, which will have an impact on social isolation, job loss and psychological and socioeconomic impact of MDR TB sufferers [6]. The WHO reports the success rate of handling MDR TB is 44.5-58% where the main cause of the failure of handling MDR TB is the non-compliance of MDR TB patients doing treatment.

Long-term management of MDR TB and the various impacts that occur is a challenge for TB sufferers and their families. This literature study aims to explore the burden felt by MDR TB sufferers and MDR TB families.

II. METHOD

Literature review of qualitative articles was carried out with a thematic approach. Data were obtained in the review by identifying, evaluating and synthesis.

- Article Search Strategy

Review protocol was developed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)-statement (www.prisma-statement.org). Search for articles was carried out in the journal database as follows: Medline, Scopus, ScienceDirect and Google Scholar (by AsW and ReS).

The keyword for search topics included “Multi drug resistant Tuberculosis”, “social”, “psychological’, “physical’, “family”, “patients”, and “qualitative research”/ “TB MDR”, “Burden”. The full search strategies for all databases can be found in Table 1. Searching and selecting articles was conducted September and October 2018.

Table 1 Table of search strategy in journal database

Database	Keyword	Results
Scopus	TITLE-ABS-KEY. #1 tb mdr OR multiresistant tuberculosis OR resistant tuberculosis. #2 physical. #3 psychological. #4 social. #5 family OR caregiver OR spouse OR patients. #6 qualitative OR phenomenological. #1 AND #2 OR #3 OR 4 AND #5 AND 6	118
ScienceDirect	#1 tb mdr OR multiresistant tuberculosis OR resistant tuberculosis. #2 burden OR impact OR effect. #3 family OR caregiver OR spouse OR patients. #4 qualitative OR phenomenological.	3
PubMed	#1 multiresistant tuberculosis OR resistant tuberculosis. #2 physical. #3 psychological. #4 social. #5 family OR caregiver OR spouse OR patients. #6 qualitative OR phenomenological. #1 AND #2 OR #3 OR 4 AND #5 AND 6	10
MEDLINE	("Tuberculosis, Multidrug-Resistant/ethnology"[Mesh] OR "Tuberculosis, Multidrug-Resistant/nursing"[Mesh] OR "Tuberculosis, Multidrug-Resistant/prevention and control"[Mesh] OR "Tuberculosis, Multidrug-Resistant/psychology"[Mesh] OR "Tuberculosis, Multidrug-Resistant/rehabilitation"[Mesh])	102

- Inclusion Criteria

Criteria for inclusion of articles in the review were: (1) use qualitative methodology, (2) focus on perceived burden of patients and or family of MDR TB, (3) mixed-method research that reports qualitative results clearly and

completely, (4) published in English. Searches are limited to journal articles in English or Indonesian. Exclusion criteria were: participants from specific patient populations such as TB patients with other disease as diabetes or HIV patients (as these studies tend to focus on MDR TB patients), and participants living in residential facilities such as care homes, nursing homes or retirement homes. The articles are limited to the last 10 years, the period 2008-2018, without limiting the place of research.

- Article Selection Procedure

The references from the different databases were imported into Mendeley, after which duplicates were removed. Each of two authors (RdT and ReS) screened half of the articles titles and abstracts to exclude articles that did not meet the inclusion criteria. In case of doubt, the article was included in the selection of papers potentially relevant to the review. Next, full texts were retrieved and further assessed for eligibility by both RdT and ReS, independently from each other. Disagreements were discussed by the two authors until consensus was reached. Reference lists of included studies were checked to identify additional relevant studies for the synthesis.

- Data Extraction

All articles were read several times before and during analysis by two review authors (RdT and ReS). These following study characteristics were extracted by ReS: information about the sample and sampling procedure, information about the data collection method and the data analysis approach, information about the focus of the study and questions asked to participants, information about the theoretical frameworks that guided the development of questions or interpretation of findings, and the main conclusions from the authors. The complete 'results' or 'findings' parts from the studies were seen as data for this review and entered verbatim into a Microsoft Excel database by RdT and ReS, simultaneously dividing the text into smaller but meaningful fragments. These fragments, thus, included quotes from participants as well as text written by the primary studies' authors, such as interpretations and clarifications of quotes, descriptions of participants' responses and descriptions of the context in which responses were given. The categories or themes of which the authors described the data were noted next to the specific fragments. Data from discussion parts (including more theoretical interpretations) were not extracted.

- Thematic Analysis

Thematic analysis was adopted from previous study [7]. There were three stages, namely free coding of the findings of primary studies; organization of these free codes into related areas to construct descriptive themes; and development of analytical themes. The three stages overlapped to some degree.

In the first stage of analysis, free coding, two authors (ReS and RdT) coded each extracted fragment according to its meaning and content independently. Two authors met to compare their codes finding, making sure that interpretations of codes were aligned. During the process of analysis, the coding scheme was discussed extensively and continuously, and adjusted and complemented if necessary. In the second stage of analysis, the free codes of all identified were combined or grouped in descriptive themes. In the third stage, these were further categorized after looking for similarities and differences between the descriptive themes and the fragments belonging to each descriptive theme.

III. RESULTS

The article search results obtained a total of eight (8) articles that fit the inclusion criteria and study topics. An initial search of the article found 233 articles which were reduced to 213 due to duplication. After screening the title and abstract, 63 articles were excluded because they did not fit the study area and 144 articles did not meet the

inclusion criteria. The total articles obtained are eight (8) articles with two (2) additional articles from Google Scholar. The process of selection process is shown in Figure 1.

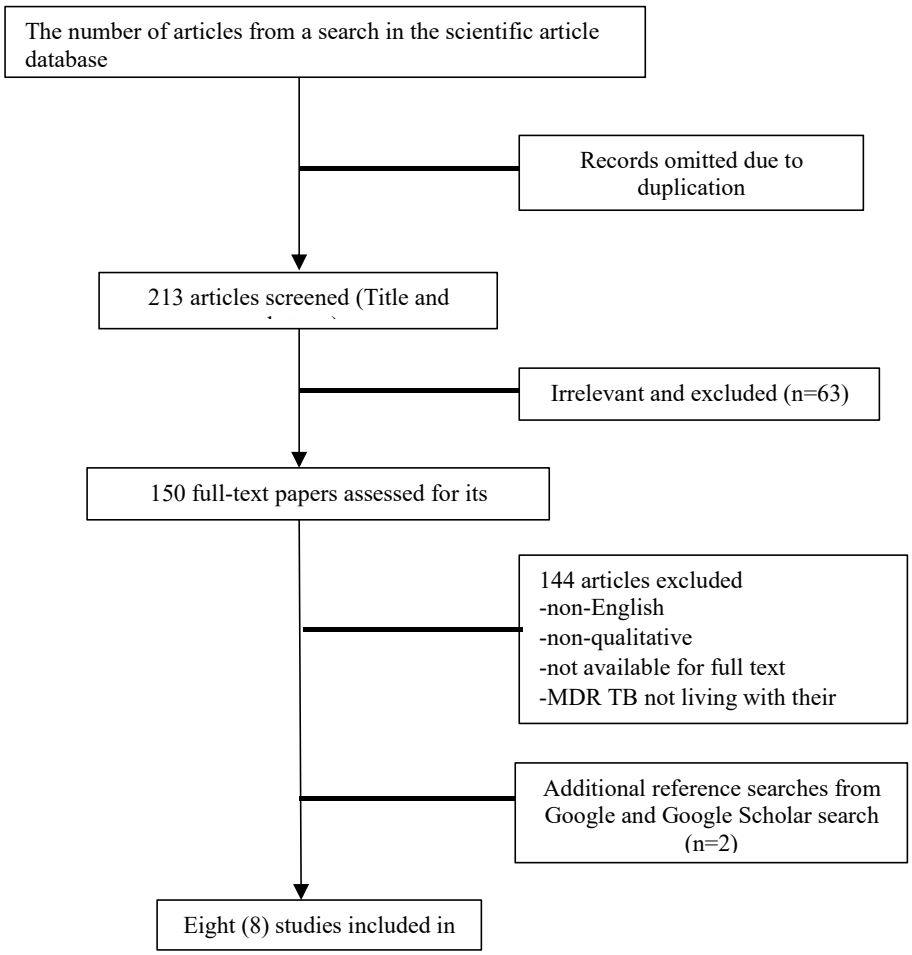

Figure 1 Flowchart of selecting articles of perceived burden of multidrug-resistant tuberculosis patients and their family: a systematic review of the qualitative literature

- Reviewed study

Characteristics and conclusions of the 48 included studies are displayed in Table 2. One study was conducted in Africa [8], two studies in India [9], [10], and other studies conducted in Uganda [11], Nigeria [12], Kyrgyzstan [13], Mexico [6] and China [14]. Participants were most frequently recruited by purposive sampling. Six studies used individual semi-structured interview for data collection, two studies used individual semi-structured interview and focus group discussion. The method of analysis consisted of content analysis or thematic coding.

- Perceived Burden of MDR TB Patients and Their Family
  - The social burden of MDR and family TB sufferers

Several studies have shown that there are social burdens felt by people with MDR TB, namely feelings of discrimination and stigma from the community, lack of support from family members and partners, from health workers [6], [9], [12], [13], staying away from family for fear of risk of transmission [12].

  - Psychological burden of MDR and family TB sufferers

Several studies show that there are psychological burdens faced by people with MDR TB, including depression, confusion, and thoughts of suicide [9], feeling unfair because they have to wear masks in the community [12], feeling hopeless, feeling worthless again [6], [10], and feeling frustrated with daily drug consumption [10]. Psychological burdens experienced by families of MDR TB patients who feel anxious when getting negative views or discrimination from others include feeling afraid [8].

- Physical burden of MDR and family TB sufferers

The physical burdens reported by people with MDR TB are discomfort due to side effects of drugs taken, such as vomiting, headaches, mental disorders [9], and feeling tired due to having to do self-protection procedures [12]**.** The physical burden felt by families of MDR TB sufferers is feeling tired in caring for sufferers [8].

- Financial burden of MDR and family TB sufferers

The financial burden felt by people with MDR TB and their families related to transportation costs, and lost their jobs because they have to follow treatment for two full years [6], [14]. The financial burden reported from the study results is that the family loses work because they have to care for sick family members [8], [11].

IV. DISCUSSION

The results of the review of several articles related to the burden felt by people with MDR TB and families of MDR TB sufferers have some similarities, such as feelings of stigma and discrimination both from oneself, others, and health workers. Stigma occurs because people with MDR TB have different attributes that cause disruption to social status, rejection and exclusion. The self-perceived stigma that comes from MDR TB sufferers causes social isolation where sufferers deliberately move away from social interaction with others [16]. This isolation is due to fear of infecting others and fear of being negatively treated by others. Discrimination from the public and health workers can cause non-compliance with MDR TB patients in completing a series of treatments[17].

The psychological burdens of MDR TB sufferers and family range from fear and frustration to depression. Other studies have shown that the level of depression in people with MDR TB is quite large with the level of depression varying depending on several factors, such as the duration of treatment [18]. The fear experienced by people with MDR TB is especially fear of rejection from others and being afraid of the future that will be lived. Patients with TB have difficulty in establishing social relationships with others because of the illness. Feeling frustrated with various drugs is also one of the causes of the risk of depression and the risk of non-compliance with the treatment of MDR TB patients.

Feelings of fear of contacting TB as well as fear of getting negative views from others are also felt by the families of MDR TB sufferers. The level of frequent contact with family members suffering from MDR TB can increase the risk of contracting TB. Contact of family members with TB sufferers shows relatively high risk of developing TB [19]. Negative perceptions and stigma were seen to discourage MDR TB patients' treatment uptake and adherence. However, it encouraged some MDR TB patients to complete their treatment in order to avoid home visits by health personnel for retrieval action.

MDR TB sufferers and families feel physical fatigue due to various treatments that must be done in the long term. Various side effects are also felt by people with MDR TB that cause physical disturbances and discomfort. The cost of treating MDR TB is high. Although there is already health insurance, costs related to transportation costs, care costs, and costs due to job loss are obstacles and burdens for MDR TB sufferers and families.

We believe this study has some important implications for care and service delivery in MDR-TB patients and their family. First, healthcare professional accurate treatment, education and counseling, provided in a non-judgmental manner, that involves family members and garners their support from the outset, is likely to enhance patients' commitment to treatment.

- Strength and Limitation

This study contributes to our understanding of perceived burden from the perception of MDR TB patients and their family as it brings together the findings of eight studies, covering views of many MDR TB patients and their family from various countries. The synthesis, therefore, provides a more universal understanding of perceived burden from the perception of MDR TB patients and their family than each study on its own. By recoding and synthesizing the reported data rather than summing up a list of identified themes, we aimed for a 'whole' greater than the sum of its parts.

Although, we understand that participant/samples diversity may affect how they characterize their perceived burden, our aim was to define the commonalities over these diverse participants. Therefore, we analyzed the quotations content of participants, not their personal characteristics. However, there are limitations to condensing such a wealth of material. A synthesis could lead to a selection of material which already is the result of a process of condensing and interpretation of primary raw data done by the authors of the studies. We refer readers to the individual papers if they are interested in more detailed discussions and interpretations of the identified and found domains. Finally, we did not perform a formal quality appraisal of the included studies. Based on a subjective overall evaluation, going from our personal experience with doing and reporting qualitative studies, we did not consider any one of the included studies as fatally flawed, so did not see a reason to exclude any of them from the synthesis.

V. CONCLUSION

This review identified four major themes related to the perceived burden by MDR TB patients and their family, namely; physical, psychological, social and financial burden. Understanding the difficulties and burdens experienced by MDR TB patients and their families is important in order to choose the appropriate intervention according to the problems that may arise due to MDR TB disease. It is important that service providers and care professionals realize that the perceived burden domains should be assessed during patients and family treatment to prevent disease exacerbation caused by psychological condition of MDR TB patients and their family.

CONFLICT OF INTEREST

The authors declare have no conflict of interest

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APPENDIX

Table 2 Characteristics of studies included in synthesis

Article title	Method	Population & sampling	Result
Household context and psychosocial impact of childhood multidrug-resistant tuberculosis in KwaZulu-Natal, South Africa [8]	Individual semi-structured interview	26 caregivers of children with TB MDR which diagnosed from hospital	Four Themes 1 Psychosocial impact of hospitalization and separation on the child and the household 2 Psychosocial impact of multidrug-resistant tuberculosis on children 3 Psychosocial impact of multidrug-resistant tuberculosis on care givers 4 Accentuated economic vulnerability of households
Patient and provider reported reasons for lost to follow up in MDRTB treatment: A qualitative study from a drug resistant TB Centre in India [9]	Individual semi-structured interview	TB MDR patients age 23-53 years	Four Themes Medications related 1. Drug effect 2. Long duration of treatment 3. Pain associated with daily injection 4. High pill load Service provider related 1. Time conflict between work and treatment 2. Service provider behavior 3. Counseling is not good 4. Access to health services Socioeconomic factors related 1. Stigma and discrimination 2. Lack of social and family support 3. Financial barriers and unemployment Patient-related 1. Lack of awareness 2. Myths and distrust about disease 3. Alcohol addiction 4. Issues of confidentiality
"Home is where the patient is": A qualitative analysis of a patient-centred model of care for multi-drug resistant tuberculosis [11]	Individual semi-structured interview	12 Healthcare receiving, nine healthcare providing and nine key informants	The perceived preference and acceptability of home-based treatment and care as a model of MDR-TB treatment by patients, family, community members and healthcare workers; the fear of transmission of other infections within hospital settings; and the identification of MDR-TB developing through poor adherence to and inadequate treatment regimens for DS-TB.
Hospitalized care for MDR-TB in Port Harcourt, Nigeria: a qualitative study.[12]	Individual semi-structured interview	11 TB MDR Patients	Patients' perspective on hospitalized care 1. Stigmatization exacerbated by treatment and support services 2. Feeling of imprisonment 3. Restricted communication and isolation disrupting patients' personal relationships 4. Fellow patients as source of physical and emotional support 5. Meeting needs through organized group action
"My Favourite Day Is Sunday": Community Perceptions of (Drug-Resistant) Tuberculosis and Ambulatory Tuberculosis Care in Kara Suu District, Osh Province, Kyrgyzstan.[13]	Individual semi-structured interview and focus group discussions	58 individual interviews and 4 people in FGD	Factors influencing treatment concordance. Stigma and access barriers
Social, economic, and psychological impacts of MDR-TB treatment in Tijuana, Mexico: a patient's perspective. [15]	Individual semi-structured interview	12 TB MDR Patients	Inability to work, social isolation and stigmatization from family and friends. The majority of participants expressed appreciation for Puentes' role in "saving their life."
" When Treatment Is More Challenging than the Disease" : A Qualitative Study of MDR-TB Patient Retention [10]	Individual semi-structured interview	36 TB MDR Patients	Struggle with prolonged treatment Strive against stigma and toward support Divergent perceptions and practices
Financial barriers and coping strategies: a qualitative study of	Individual semi-structured interview and	Five focus group discussions and 47 in-depth interviews	Financial barriers and inequalities in accessing TB/MDR -TB care Financial burden in spite of "free" TB and MDR TB treatment

accessing multidrug resistant tuberculosis and tuberculosis care in Yunnan, China [14]	focus group discussions	with purposively sampled TB and MDR-TB patients and healthcare providers	and diagnosis Costs of accessing care Strained relationships and social stigma Impoverishment Direct and indirect family support