A Systematic Review of Stigma Among Tuberculosis Patient And Its Effect

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Abstract---The cause of success in the process of treating tuberculosis patients is the emergence of stigma. Stigma has been argued as a barrier to tuberculosis therapy, because with the stigma the patient will become more closed, withdrawn and difficult to monitor treatment. The purpose of this systematic review is to determine the stigma among tuberculosis patient and its effect. This study was used systematic review with literature search using online reference databases: ProQuest, Sciencedirect and SCOPUS. The keyword that used in this research was "tuberculosis or tb and social or public stigma". A full of literature search and study selection process in accordance with the PRISMA guidelines. Studies will be a part of this research if they explain about stigma among tuberculosis patient. The review of 15 articles that met the criteria showed that many tuberculosis patient get negative stigma in their life. The level of stigma mostly high. In general, the majority of the community indicated that they would treat TB patients differently for the rest of their lives, do not want those with TB to play with their children, do not want to eat or drink with friends who have TB, and are uncomfortable about being close to those with TB. The stigma among tuberculosis patient is in high rate, so stigma reduction should prioritize the involvement of clients living with the stigmatized condition or behavior and health workers living with stigmatized conditions and should address both individual and structural level stigma.

Keywords: tuberculosis, stigma, effect of stigma

I. INTRODUCTION

Stigma is a major social determinant of health that drives morbidity, mortality, and health disparities, and has been described by the World Health Organization as a 'hidden' burden of disease [1]. Stigma is characterized by cognitive, emotional, and behavioral components and can be reflected both in the attitudes, often conceptualized as perceived, anticipated, or internalized stigmas, and experiences, including enacted or experienced stigmas affecting a particular trait, among individuals. Perceived stigma refers to a person's understanding of how others may act towards, and think or feel about, an individual with a certain trait or identity. Anticipated stigma refers to expectations of stigma experiences happening in the future. Internalized stigma refers to the individual level process of awareness, acceptance, and application of stigma (to oneself). Finally, experienced or enacted stigma refers to discriminatory acts or behaviors [2].

Globally, an estimated 10.0 million (range, 9.0–11.1 million) 2 people fell ill with TB in 2018, a number that has been relatively stable in recent years. The burden of disease varies enormously among countries, from fewer than five to more than 500 new cases per 100 000 population per year, with the global average being around 130. Geographically, most TB cases in 2018 were in the WHO regions of South-East Asia (44%), Africa (24%) and the Western Pacific (18%), with smaller percentages in the Eastern Mediterranean (8%), the Americas (3%) and Europe (3%). Eight countries accounted for two thirds of the global total: India (27%), China (9%), Indonesia (8%), the Philippines (6%), Pakistan (6%), Nigeria (4%), Bangladesh (4%) and South Africa (3%). These and 22 other countries in WHO's list of 30 high TB burden countries accounted for 87% of the world's cases [1]. According to research conducted by Orovwigho [3] conducted in Enugu Nigeria that more than half or as many as 65.1% of pulmonary TB patients have low self-esteem, this is partly the perception

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about pulmonary TB disease as an infectious disease in stigma by the social environment. According to Flanagan [4] in his study conducted in Brazil as many as 20% of pulmonary TB patients have low self-esteem because of the stigmatization of negative emotions, social rejection and self-isolation.

Stigma is a negative perception that individuals have that they cannot be socially acceptable [5]. According to Rusch, et al [6], stigma is divided into two namely community stigma (public stigma) and self stigma (self stigma). Community stigma or also called social stigma consists of stereotypes, prejudices and discrimination that lead to negative evaluations to distinguish individuals based on something. Whereas self stigma has the same components as community stigma. Self stigma (self stigma) is a negative perception that is owned by individuals that it cannot be socially accepted, which can cause a decrease in self-esteem, so individuals tend to withdraw from the environment and less interacting with the social environment [7].

This paper presents a scoping review of the literature on the health consequences of stigma and effect of stigma. The main purpose of this research is to explore the social or public stigma on tuberculosis patient and its effect. In so doing, this review highlights how the community stigma of patients with pulmonary tuberculosis and how the effects of the stigma given by the community to tuberculosis patients.

II. METHODS

- Searching strategy for studies

This systematic review includes original articles that discuss about social or public stigma on tuberculosis patient and the effect of the stigma to the patient. A systematic literature search was carried out in a number of major databases such as Proquest, Sciencedirect and Scopus. A full of literature search and study selection process in accordance with the PRISMA guidelines. Articles will be a part of this study if they are talking about social or public stigma on tuberculosis patient and the effect of the stigma to the patient.

- Study selection

The search results by using a keyword obtained 320 articles and after we limited with the year (2016-2020) we get 121 articles. 15 articles meet the inclusion criteria. Each study contains stigma on tuberculosis patient. Studies that use another theme are excluded from this research. All study selected by the criteria of: (1) document type was an original article; (2) Source from journals; (3) article in English; (4) Article available in full text.

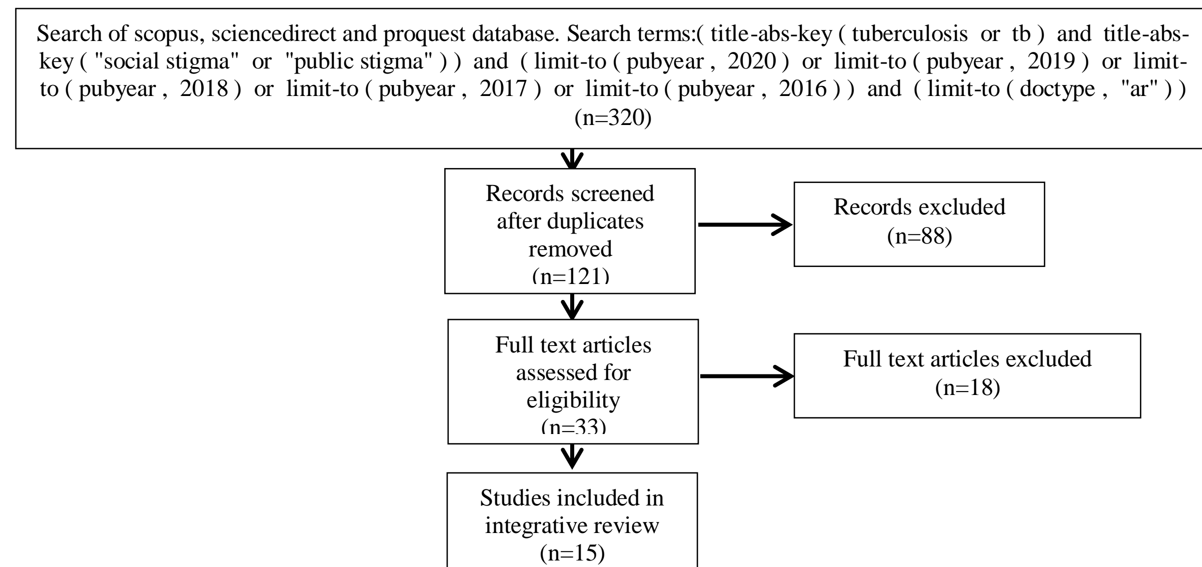

Figure. 1: flow diagram of search results for tuberculosis social stigma and its effect with the PRISMA guidelines.

Inclusion criteria in the literature are studies about social or public stigma on tuberculosis patient and the effect of the stigma to the patient with a limitation of the years used for the past 5 years (2016-2020). The outcome produced are social or public stigma on tuberculosis patient and the effect of the stigma to the patient. Ethical issues in preparing the manuscript of systematic review are following 1) avoiding plagiarism; 2) avoiding duplicate in publication; 3) Transparancy in searching, screening, processing and evaluating articles.

III. RESULTS

- General features and type of study

From 15 articles, data collection was carried out in India as many as 5 articles, China 4 articles, Iraq 1 article, England 1 article, Bangladesh 1 article, South Africa 1 article, Tanzania 1 article, and Lesotto 1 article. The number of participants in each article is more than 150 participants for quantitative and more than 10 for qualitative. All articles are talking about social or public stigma on tuberculosis patient and the effect of the stigma to the patient. Most articles use randomized to get the participants**.**

Table 1. General characteristics of selected studies (n=15)

Category	N	%
Year of publishing		
2016	1	6.67
2017	7	46.66
2018	3	20
2019	4	26.67
Topic of study		
Social stigma	8	53.33
Effect of stigma	7	46.67
Type of social stigma		
Social isolation	3	37.50
Verbal abuse	2	25
Different social treatment	3	37.50
Effect of stigma		
Low treatment adherence	3	42.86
Psychological impact (depressive, stress, and fear)	4	57.14
Type of study		
Cross-sectional	8	53.33
Qualitative	4	26.67
Descriptive	2	13.33
Mixed Method	1	6.67

- Tuberculosis Stigma

The 15 articles discuss about social or public stigma on tuberculosis patient and the effect of the stigma to the patient. In general, the majority of the community indicated that they would treat TB patients differently for the rest of their lives, do not want those with TB to play with their children, do not want to eat or drink with friends who have TB, and are uncomfortable about being close to those with TB.

Our results indicated that TB stigma mainly manifested through social isolation and avoidance due to fear of contagion, gossip and verbal abuse, failed marriage prospects, and neglect from family. It can inferred in patient love story too. The mechanism at the heart of the theory is TB's disruptiveness to the gendered roles of wife (or daughter-in-law) and mother. It is this disruptiveness that gives legitimacy to the rejection of marriage to a woman with TB.

- The Effect of Stigma on Tuberculosis Patient

The main components of stigma were fear, self-isolation, ostracization, loss of status in the community, and discrimination by providers. Participants described the cultural context in which stigma operated as characterized by a general lack of health knowledge, cultural beliefs about TB, and engendered beliefs about disease in general. Both genders described some similar effects of stigma, including relationship difficulties and specifically challenges forming new relationships, but many effects of stigma were distinct by gender: women described challenges including assumptions about promiscuity and infidelity, as well as rejection by partners, while men described survival challenges. Stigma acted as a barrier to care through a cyclical pattern of stigma and fear, leading to health-seeking delays, with resulting continued transmission and poor health outcomes that further reinforced stigma. The impact of stigma and depressive symptoms on medication adherence was significant.

IV. DISCUSSION

- Tuberculosis Stigma

Table 1 shows that in this study TB sufferers who experienced stigma in the form of social isolation totaled 37.5%. This shows that people discriminate against tuberculosis patients by giving labels to stay away from them. Some tuberculosis patients often report discrimination from the community. This is because people feel afraid of contracting the disease. Patients assess whether others will avoid themselves or maybe some patients will avoid by rarely socializing in the community. Although there are variations in the socio-cultural and socio-demographic factors in each country that contribute to determining the stigma of being the main cause is a concern about the transmission of tuberculosis, besides the lack of knowledge about the route of tuberculosis transmission can also cause stigma [8].

Patients who experienced verbal abuse in this study amounted to 25%. This can be interpreted that until now there are still many social communities who say words that are inappropriate for tuberculosis sufferers. Related research conducted by Cremers et al (2015) that tuberculosis sufferers who experience stigma are treated differently by relatives / neighbors / friends after disclosure of suffering from tuberculosis such as facing ridicule, derogatory comments, scrimination, social exclusion, and social isolation. Social exclusion is often triggered by the opinion that tuberculosis is highly contagious which then manifests in separate eating and drinking, avoids sexual intercourse, exclusion from school or workplace activities [9].

Another stigma given by the community in this study of TB sufferers is the existence of different treatments for TB sufferers, amounting to 37.5%. This other treatment is felt to be very different between TB sufferers and non-TB sufferers. People with TB are often treated with irreverence, receive harsh words and even excluded from the social community. Even related to marriage there are also people who refuse to marry women who suffer from tuberculosis. Based on the research of Hatherall et al, It is this disruption that gives legitimacy to the rejection of marriage to a woman with TB. Whether or not this mechanism results in a negative impact of TB on marriage prospects depends on a range of contextual factors, providing opportunities for interventions and policies [10].

In general, the majority of the community indicated that they would treat TB patients differently for the rest of their lives, do not want those with TB to play with their children, do not want to eat or drink with friends who have TB, and are uncomfortable about being close to those with TB. Most studies on stigma, including those on HIV and TB stigma, are rooted in the work of Erving Goffman. He defined stigma as a discrediting social label that changes an individual's self-image and disqualifies him or her from full social acceptance [11].

- The Effect of Stigma on Tuberculosis Patient

Table 1 shows that in this study the psychological effect of community stigma on TB sufferers was 57.14%. Many factors can affect this condition. Negative views of society to TB sufferers can cause stress stress for patients. Pulmonary TB can also cause psychosocial problems, psychosocial effects include psychological problems related to illnesses such as feeling bored, lacking motivation, to serious mental disorders such as major depression. Other psychosocial problems are stigma in the community, feeling fear of the incurable disease, feeling ostracized, and not confident, as well as economic problems [12]. These things certainly make pulmonary TB patients experience stress due to pressure from both inside and outside [13]. Unresolved stress will stimulate the hypothalamus to secrete corticotropin releasing factor (CRF) which causes the pituitary gland to secrete adrenocorticotropin releasing hormone (ACTH) which stimulates the adrenal cortex to secrete cortisol. Increased excessive cortisol secretion in patients with pulmonary TB can cause complications, decrease the immune system, and excessive metabolism [14].

Stigma can cause non-compliance with treatment in TB patients by 42.86% in this study. In the aspect of treatment (curative), the success of TB treatment is influenced by several factors, including medical and non-medical factors. Medical factors include first complaint before treatment, comorbidities, side effects and drug retention, while non-medical factors include age, type of work, communication of educational information, attitudes of health workers, affordability of treatment, Drugs Supervisors (PMO) and regularity of taking medication [15]. A literature review on research that examined TB treatment adherence and found four main factors that were interrelated and influenced TB treatment adherence. These four factors include structural factors (including poverty and gender discrimination), social context, health service factors, and personal factors [16]. Factors related to non-compliance with TB / HIV treatment, namely: socioeconomic conditions and personal behavior. Non-compliance with TB treatment

was due to patients feeling better and thus stopped treatment before the allotted time. Not infrequently, this is triggered by a lack of financial support for the continuity of the treatment. However, aspects of social support are considered important for medication adherence [17].

Stigma acted as a barrier to care through a cyclical pattern of stigma and fear, leading to health-seeking delays, with resulting continued transmission and poor health outcomes that further reinforced stigma. The impact of stigma and depressive symptoms on medication adherence was significant. Many experts believe that it will be difficult to find the estimated 4 million missing TB cases without addressing TB stigma.1,4 Experts also believe that the full potential of new drugs and regimens for multidrug-resistant TB (MDR-TB), paediatric TB and latent tuberculous infection (LTBI) cannot be realised without addressing TB stigma [18].

V. CONCLUSION

The stigma among tuberculosis patient is in high rate, so stigma reduction should prioritize the involvement of clients living with the stigmatized condition or behavior and health workers living with stigmatized conditions and should address both individual and structural level stigma.

CONFLICT OF INTEREST

No conflicts of interest have been declared.

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