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Research Article

Parent's Stigma Towards Childhood Tuberculosis: A Multicenter Survey from Eastern Bandung Regency

Azalia Melati Putri[1*] | Titin Rohmatin[2] | Grashiva Putri Karina[3] | Tika Asri[4] | Desi Apriani[5] | Windy Rakhmawati[6]

[1-5]Bachelor of Nursing Program, Faculty of Nursing Universitas Padjadjaran, Bandung, West Java, Indonesia

[6]Department of Pediatric Nursing, Faculty of Nursing Universitas Padjadjaran, Bandung, West Java, Indonesia

***contact**

azalia19002@mail.unpad.ac.id

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Abstract

Aims: Tuberculosis-related stigma negatively influences tuberculosis prevention programs such as delayed diagnoses, poor treatment adherence, and decreased quality of life of patients. This descriptive quantitative study aimed to describe the stigma towards tuberculosis among parents.
Method: A total of 30 samples taken through accidental sampling were parents who had children (0-14 years) with tuberculosis who had been treated at the public health centers. A questionnaire adapted from Van Rie TB Stigma Scale (VTSS) was used and analyzed using descriptive analysis.
Result: Most parents (76.6%) had lower levels of stigma, while the others scored higher levels. Lower stigma levels can be caused by a mature mindset, good knowledge of TB information, and indicates higher hopes from parents to increase their care level for children's development, health-seeking behavior, and support for children's TB treatment until it is completed. Accordingly, higher stigma levels from parents might be a result of several external factors that can increase the lack of motivation for health-seeking behavior in their children's TB treatment.
Conclusion: The role of health workers is very important in reducing stigma. Health education about prevention and treatment of childhood tuberculosis is still needed because it is a source of fear and high stigma against childhood tuberculosis in society.

Keywords:
Childhood Tuberculosis; Parents; Stigma

INTRODUCTION

Tuberculosis is a chronic infectious disease that often causes stigma. Stigma is a negative perception in individuals that causes a decrease in self-esteem (1). Stigma in tuberculosis patients was known as one of the main cause of delayed diagnosis, failure to seek treatment, poor adherence, dropping out of treatment, as well as decreased patient quality of life (2). The perceived stigma considerably impacts health, making patients reject their disease and medical services, causing an increase in immunity ineffectiveness and disease transmission (3). Some examples of stigma in TB patients include labeling, discrimination, rejection, and exclusion (4). The notion that TB is a frightening and disgusting disease causes families and

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caregivers to get stigmatized (5). This can occur due to the transmission of TB through droplets and the long-term treatment process that patients must undergo together with their families and caregivers who care for them (6). Therefore, stigma in TB patients is one of the burdens for patients, families, and caregivers.

Indonesia has the third-highest number of TB cases in the world. Based on Indonesian TB data (2020), it was found that the estimated number of new TB cases in 2020 was 845,000 cases, but only 69% of the total cases were confirmed including 42,187 TB cases among children. Data of the Central Statistics Agency (2021) shows that West Java is one of the provinces with the highest number of childhood TB cases with 11.482 cases. Bandung Regency is one of the regions in West Java Province with the highest number of child TB cases with 1,611 cases or 76% of the total number of cases in the Province (7,8). Unfortunately, this area's Case Notification Rate (CNR) decreased significantly from 91.1% in 2019 to 56.6% in 2020 (8). This can occur due to inappropriate health-seeking behavior of TB patients which is strongly influenced by individual factors including stigma (9,10). Even though there is a decrease in the number of cases found, the actual number of childhood TB patients may be much higher than expected (11). This is because TB cases in children may often come from adults, has latent characteristic, and difficult to diagnosed.

Childhood TB has different characteristics from TB that occurs in adults. Recent study results show that children tend to be easily infected with TB and develop worse conditions due to immune factors that have not yet fully developed, especially in children under 5 years old (12,13). Even though they have been vaccinated with BCG, children would be at risk of being infected with TB if they are not accompanied by balanced nutritional intake and a strong immune system (14). In addition, establishing a diagnosis of TB in children tends to be challenging because the typical clinical symptoms are not very visible and it is also difficult for children to excrete sputum independently for examination (15). Meanwhile, Childhood TB treatment in children is very dependent on parental intervention and monitoring, especially with regard to medication adherence, home environmental conditions, provision of adequate nutrition and regulation of activity and rest (16). This is in line with research results which state that successful TB treatment in children can be achieved through good family knowledge and support (17). Poor family knowledge can trigger stigma, resulting in a child's lack of treatment support and slowing the healing process.

Stigma negatively impacts TB patients and their families in various ways, such as hindering public health efforts to prevent and treat the disease (18,19). Stigma can occur in various forms such as hopelessness, fear of identity, low self-esteem, guilt, self-isolation, anxiety, depression, unfair treatment, and discrimination (20–22). This condition may influence stigmatized individuals to delay health-seeking behavior and keep their condition secret (18). Several previous studies have stated that stigma against TB can lead to reduced TB patient's adherence to treatment programs, disrupted patient's quality of life and poorer treatment outcomes (21,23,24). High stigma against TB in the community can hinder the process of treatment especially for childhood TB patients due to the lack of support from families and communities for sufferers (25). Whereas, with optimal support from family and society, TB sufferers can be diagnosed promptly and treated effectively (26,27).

Family support is one of the factors that can impact stigma levels in children with TB. Poor family support can lead patients to be more isolated, feeling denied in daily activities, decrease life satisfaction and social confidence (28). Meanwhile, if family support is given adequately, it can help

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reduced stigma because patients will feel more cared for and also will help them to gain motivation and confidence to carry out treatment without feeling rejected or wasted by their own families (29). Support can be given by providing medical expenses, monitoring regularity of medication consumption, education about TB disease to children, and giving affection and attention by parents during treatment period (30).

Bandung district ranks second with the highest prevalence of TB cases in children in West Java (54). The eastern region of Bandung Regency is an industrial area with a high population density and most of the people have a middle to lower socioeconomic level which is a factor that can increase TB cases (8). In addition, inadequate residential environmental conditions such as lighting, ventilation, humidity and poor residential density in the area also increase the risk of TB transmission. (8,31). The Cileunyi and Cicalengka sub-districts are known to be areas with high suspected cases of TB in the eastern region of Bandung Regency (8). This can contribute to the high cases of TB in children, considering that TB transmission in children mostly originates from adult patients (32). Therefore, we condudted a multicenter study in the eastern region of Bandung in both subdistrict.

Based on the description of the phenomenon that has been presented, researchers conducted a brief interview with 3 nurses in charge of the TB management program and 3 parents who attend regular TB treatment for their children from 3 different study locations. The results of the interviews show that there are still negative perceptions in society about TB. The interviewed parents said they were embarrassed to talk about their child's illness because TB was often seen as a disgrace and something frightening. Following up on the results of interviews and insufficient scientific evidence, it is important to know the picture of stigma in parents who have children with Tuberculosis (TB) in the eastern Bandung Regency.

METHODS

Study Setting and Design

The design used in this study is descriptive quantitative to determine the picture of stigma towards childhood TB among parents who have children with Tuberculosis (TB) disease. A total of 3 public health centers (Puskesmas) located in the eastern Bandung Regency (including the areas of Cileunyi, Cinunuk, and Cicalengka) were involved in the research process which was carried out from July to August of 2022.

Population and Sampling Method

The population involved in this study were parents who had children with TB disease under the age of 14 years and went to study locations in the eastern Bandung Regency in the range of 2020-2022. Accidental sampling was used as a sampling technique with the number of respondents involved as many as 30 people. This technique was chosen because the sample is homogeneous, and the number of respondents obtained is sufficient to represent the data quantitatively. Therefore, a sample with this minimum number (30 sample) is recommended for a quantitative study with a cross-sectional approach (33)

Data Collection

Researchers collaborated with the Puskesmas Cinunuk, Cileunyi, and Cicalengka in the data collection process after obtaining complete research approval from Badan Kesatuan Bangsa dan Politik (National Unity and Politics Agency) and Head of Health Office Bandung Regency. Researchers held meetings with nurses in charge of TB and cadres working in the Cinunuk, Cileunyi, and Cicalengka Health Centers to obtain data on Childhood TB patients who were eventually included as research samples. Researchers visited the nearest childhood TB patient's house one by one to collect data using a questionnaire.

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The stigma-related data was collected using an instrument developed by Van Rie et al. (2008) and adapted by Suandi (2012) (25) to measure stigma in TB patients. This instrument consists of 3 sub variables, namely concern about the transmission of disease, values and attitudes related to feelings of shame. As many as 9 question items that have been adapted to the research respondents from the original 12 questions are measured using a four-level Likert scale: strongly disagree (0), disagree (1), agree (2), and strongly agree (3). All responses are summed up to make a stigma score with higher responses indicating a higher stigma.

Data Analysis

The measuring results of this instrument are classified into lower stigma and higher stigma based on the mid-point of the total instrument score. Lower stigma can be determined if the respondent obtains a score <13.5 or in the range (0-13) and higher stigma can be determined when respondent obtains a score >13.5 or in the range (14-27). Data analysis in this study used univariate analysis which produced data in the form of frequency and percentage distribution of the variables studied. This process is carried out through a data processing application.

Ethical Considerations

This research was approved by the Research Ethics Committee of Universitas Padjadjaran with the issuance of an ethical license number 516/UN6.KEP/EC/2022. Respondents gave written consent before the data collection process was carried out.

RESULTS

Respondent Characteristics

Characteristics of the respondents involved in this research (parents who have children with TB) are based on individual aspects (age, occupation, education, number of biological children, and type of family), ability to access health services (ownership of health insurance and mileage), and the status of children with TB (age) as shown in Table 1.

Table 1. The Characteristics of Parents of Children with TB (n=30)

Characteristics	Total of Respondents	
	n	%
Age (years old)		
15-34	16	53.3
35-65	14	46.6
>65	0	0.0
Occupation		
Employed	13	43.3
Unemployed	17	56.6
Educational Status		
Elementary School	4	13.3
Junior High School	8	26.6
Senior High School	11	36.6
Diploma	1	3.3
Bachelor	6	20.0
Number of Biological Children		
1	10	33.3
2	9	30.0
3	8	26.6
4	1	3.3

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>5	2	6.6
Health Insurance Ownership		
Covered Person	20	66.6
Uncovered Person	10	33.3
Distance from Home to Healthcare Facility		
1-5 kilometers	24	80.0
6-10 kilometers	5	16.6
>10 kilometers	1	3.3
Age of child with TB		
0 – 1 months	0	0.0
1 months – 1 years	4	13.3
1 – 3 years	5	16.6
3 – 6 years	8	26.6
6 – 12 years	9	30.0
12 – 18 years	4	13.3

Table 1. shows that some of the respondents are aged 15-34 years (53.3%), some of them are not working (56.6%), a small number of them have high school education (36.6%), a small number of them have only children (33.3%), most of the families are nuclear families (60.0%), most of them have health insurance (66.6%), most of them are within 1- 5 kilometers to the nearest health service (80.0%), a small proportion of children aged 6-12 years (30.0%) with immunization status, most of them are complete (90.0%) and receive exclusive breastfeeding for 6 months (80.0%).

Description of Parents Stigma Towards Childhood TB

Parents stigma towards childhood TB is presented based on two categories namely, higher stigma and lower stigma as shown in Table 2.

Table 2. Distribution Frequency of Parents Stigma Towards Childhood TB (n= 30)

Category	Total of Respondents	
	n	%
High Stigma	7	23.3
Low Stigma	23	76.6

Table 2. shows that most of the parents have a lower level of stigma towards Childhood TB (76.6%) and only a small proportion of parents have higher level of stigma towards Childhood TB (23.3%).

Table 3. Distribution Frequency of Parents Stigma Towards Childhood TB Based on Each Domain (n= 30)

Domain	Total of Respondents	
	n	%
Fear of Disease Transmission (Distancing behaviors)		
High	22	73.3
Low	8	26.6

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Values and Attitudes related to Shame Feelings (Feeling hurt, sad, and sinful)		
High	12	40.0
Low	18	60.0
Disclosure of Disease Status (Feeling afraid to talk)		
High	4	13.3
Low	26	86.6

Table 3. shows that most parents experience fear of their child's TB transmission by trying to keep their distance from other people (76.6%), most parents have low values and attitudes related to feeling ashamed of their child's TB (60.0%), and most parents are not afraid to reveal their child's disease status (86.6%).

DISCUSSION

This study found that most parents had a lower level of stigma, and some parents had a higher level of stigma (table 2). This result in line with research conducted by Sari (2018), which states that stigma in TB patients tends to be low (83.87%) due to the influence of respondent's treatment duration that around 3 months (1). However another research results (34,35) shows that the vast majority of respondents who participated experienced a high stigma. Low stigma can be related to the demographic status of the respondents in which more than half of them are middle-aged adults (15-34 years old), most of them are unemployed and some of them have at least a high school education (table 1). The study results show that early adulthood parents tend to have a mature mindset and care more about children's development, making it easier to receive information (36,37). In addition, parents with a higher education level tend to have broad insights because they have good ability to process information (37,38). As already reported, all respondents in this study were parents who had children with TB disease and had previously undergone treatment at the Puskesmas. Although work is often associated with education and broader insights, parents who are not working have more time to care for their children and have greater potential to access information about TB from various sources. This allows parents to gain more experience and better information than other parents. Good knowledge about TB can support patients and their family to have low stigma. According to Pasek (2013), someone with good knowledge about TB tends to positively perceive TB treatment programs (39).

High stigma can be associated with external support from the surrounding environment (40). Even though parents have received education about TB in their children from health workers during their child's treatment, high stigma can be triggered by a lack of support from those closest to them, for example from friends, relatives, and the community around where they live. This is as stated in the research by Chiang et al. (2015) in which TB patients and their families tend to experience stigmatization of TB from those around them by being the subject of contemptuous stares, gossip, and avoidance (41). On the other hand, results of other studies also explain that high stigma can also be associated with family type and living conditions (rural) (42). This is consistent with the characteristics of the respondents in this study where some parents are nuclear families living far from the center of Bandung Regency (rural).

Even though most parents have low stigma against childhood TB, high stigma for specific domain is still high among most

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parents. Based on our results, most parents are trying to keep their children away from other people because they are worried about childhood TB transmission (table 3). Parents' knowledge and experience regarding TB disease which can be easily transmitted through air and droplets may be the background of this behavior (43). The tendency of children to contract TB due to immune factors that are not yet fully formed can cause concern for parents (44). In addition, the development of more severe disease in children encourages parents to be more protective so they try to keep their distance, especially from other people who are suspected to transmit TB (45). On the other hand, the study results show that some parents still feel hurt, sad, and sinful because their children are infected with TB (table 3). This can be caused by parents' ignorance about the transmission, causes, and treatment of childhood TB patients (46). In addition, TB disease, which is synonymous with weight loss and weakness, causes parents to feel afraid and embarrassed if their child's disease status is known by those around them (1). As for most parents who are not afraid to reveal their child's disease status to their relatives and those around them, it is very likely due to the similarity of experience that previous TB survivors had. This is as previously known that the eastern region of Bandung district is an area with quite high TB cases (8). This allows the exchange of information and experiences from survivors and their families considering that TB cases are quite common in this area. This assumption is supported by a study stating that parents with TB tend not to want to tell their children's condition to their families and relatives who do not understand the condition of their child's disease (47).

Low stigma, as shown in the results of this study, indicates high expectations in treatment and shows that a stigma reduction program should transform stigma as a support (48). If the stigma shows a low result, it can be a determinant that impact health-seeking behavior and illness management. In addition, low stigma also shows that disclosure of disease status is not a big deal for respondent and show high expectations that stigma can be turned into support (49). Even so, there are still some parents who have high stigma and still need support.

TB stigma contributes to determinants of individual health (2). Stigma is a negative label given by a person or group of people to another person or certain group, usually related to a chronic and infectious disease (50). Stigma can have negative impacts such as depression, sadness, shame, guilt, poor morale, fear of the disease, hopelessness that indicates low self-esteem (4). Furthermore stigma can limit interact of a person with others so they will feel inferiority, feelings of being shunned, lack of ability to solve problems and making decision (1) Thus stigma is often be the main barrier to accessing health care, resulting in diagnostic delays and difficulty to manage disease and complete treatment (51).

Stigma that is not resolved will reduce the child's ability to fulfil growth and development, especially the social aspect because the child is unable to socialize with an environment that rejects themself. TB-affected children often faced a lack of uneasiness and understanding in social environment, while being recognized TB in children is under researched problem and scarce in research areas (3). TB stigma can impact children include low self-esteem, discrimination, social exclusion, and isolation that can decreased social status, decreased quality of life, and difficulties treatment adherence (52). The results are in accordance with other studies which show that family support has an effect on increasing adherence to treatment of TB patients by up to 20 times more adherent (53,54). The important role of the family, especially parents in forming positive perceptions of patients towards TB can encourage them to be more open in

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accepting treatment programs to completion (55).

The role of parents, communities, and nurses is important in reducing stigma in childhood TB control. Interventions that can be carried out by parents and the community, for example, try to find information about tuberculosis, such as treatment, prevention of transmission, and become a support system in improving the quality of life of children (56). The role of nurses that can be done is by providing health education to children, parents, families, and the community. Through health education, it can provide knowledge and reduce stigma about tuberculosis (40). In addition to health education, another role for nurses is to provide support to people who are stigmatized. The support given to patients is one of the important things, considering that stigma concerns the values and attitudes of the individual.

CONCLUSION

Most parents who have children with TB in the eastern region of Bandung Regency have a low stigma against TB in their children. This indicates that individual values, attitudes, and disclosure of child TB disease status are not a major obstacle for parents, so the low stigma towards parents can be turned into support for child TB patients. Even so, there are still some parents who have a high stigma against TB in children, especially related to fears of disease transmission. A correct understanding of how TB is transmitted and support from various parties such as health workers and educational institutions for childhood tuberculosis patients and their parents is needed to reduce stigma and support their treatment process. Further assessment is needed at a larger sample size to explore the stigma experienced by child TB patients and the TB stigma that exists in the community, considering that these two aspects are important in supporting the TB treatment process.

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