

Stigma in Tuberculosis Sufferers: A Study in Simeulue Regency, Aceh Indonesia

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Abstract

Tuberculosis is an infectious disease and has become a public health problem globally. This study aims to determine the factors associated with Stigma in patients with Tuberculosis in Simeulue Aceh Regency. This research uses a cross-sectional study approach. The study population was patients with Tuberculosis, totaling 112 people in 10 sub-districts in Simeulue Regency. The number of samples is 92 people. The research instrument consisted of respondents' demographics, knowledge, perceptions, psychological factors, socio-cultural, and Stigma. The analysis used the Chi-Square test with a significance level (α) 0.05. The results showed that there was a significant relationship between knowledge (p-value = 0.007), perception (p-value = 0.027), psychological factors (p-value = 0.035) and socio-cultural factors (p-value = 0.006) with stigma in suffered tuberculosis. This study concludes that knowledge, perception, psychological aspects, and socio-culture significantly correlate with Stigma in patients with Tuberculosis in Simeulue Regency. The socio-cultural aspect is the most dominant sub-variable associated with Stigma with a p-value of 0.006 <0.05.

Keyword: Stigma, Tuberculosis, Patient, Simeulue

Introduction

Tuberculosis (TB) is one of the public health problems that are a global challenge. Tuberculosis is an infectious disease caused by the bacterium *Mycobacterium tuberculosis*⁽¹⁾. The Sustainable Development Goals (SDGs) in 2015 emphasized that dangerous contagious diseases such as TB are one of the main concerns of health development goals⁽²⁾. Globally, WHO noted that in 2017 there were 6.3

million new cases of Tuberculosis. This figure is equivalent to 61% of the incidence of Tuberculosis globally, which is 10.4 million. The number of Tuberculosis sufferers has increased from the previous year, which was 9.6 million people. In addition, the number of deaths caused by Tuberculosis globally is 40 people per 100,000 world population⁽²⁾.

In Indonesia, the number of people with Tuberculosis is also high. In 2017, the number of sufferers was 391 per 100,000 population, with a death rate of 42 per 100,000 population, and the number of new cases found was 425,089 cases. This figure increased from the previous year, namely in 2016 as many as 360,565 patients. The highest number of reported cases occurred in provinces with large

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populations: West Java, East Java, and Central Java. Tuberculosis cases in the three provinces accounted for 43% of the total TB cases in Indonesia ⁽³⁾.

In Aceh Province, the number of tuberculosis sufferers is also quite high. Aceh Health Profile data in 2017 showed that the number of pulmonary tuberculosis cases continued to increase, from 5,072 cases in 2016 to 7,342 cases in 2017. The success rate of tuberculosis treatment in Aceh Province was reported to be 86.7%. This figure is still below the target national government set by the central government is 90%. These data indicate that there are still many cases of Tuberculosis patients in Aceh Province who die, drop out of drugs, and/or are not evaluated properly. The highest tuberculosis cases were reported in Banda Aceh City (304 cases), then Subulussalam (259 cases), Simeulue Regency (221 cases), Gayo Lues (216 cases), and North Aceh (213 cases). The lowest was reported in Bener Meriah Regency as many as 41 cases ⁽⁴⁾.

In 2018, the number of Tuberculosis sufferers had reported in Simeulue Regency as many as 104 cases. This figure has increased by 112 cases ⁽⁵⁾. Based on sub-districts, the highest tuberculosis cases were found in East Simeulue District with 39 cases, Salang District with 24 cases, West Simeulue District with 12 cases, Alafan District with 9 Teluk Dalam District with 8 (eight) cases ⁽⁵⁾.

Health problems caused by Tuberculosis are a major concern for all health workers, including community nurses. Until now, Tuberculosis is still an infectious disease with the highest mortality rate, so it requires complex treatment. Tuberculosis management is not only from treatment but also from prevention. In social life, the prevention aspect has the most fundamental role in reducing the number of

Tuberculosis sufferers. It is in accordance with the role and function of community nurses as implementers of nursing services and as health educators ⁽⁶⁾. In general, the management of Tuberculosis in the community focuses more on treatment based on new case findings. Its causes the program to be run less effective in eliminating the number of Tuberculosis sufferers.

For this reason, the active role of community nurses in preventing and providing health promotion to the community is very necessary. Health promotion is part of the public health program in Indonesia, not only a process to raise public awareness in terms of increasing knowledge in the health sector but also changing good behavior in the community and other community organizations. According to Mubarak, besides promoting and providing health education to the community, family and community support are important in preventing and treating tuberculosis sufferers. This factor becomes social support that greatly affects the physical and mental readiness of tuberculosis sufferers. The family is included in the social support system and is considered a resource to convey health messages ⁽⁷⁾.

The family and community's support can be positive but can also appear as a stigma. Stigma is a social process in assumptions or personal experiences of individuals related to certain health problems. Negative Stigma is high in society, which impacts the lack of self-esteem for sufferers, humiliation, discrimination, and being exiled from social life in society ⁽⁸⁾. Negative Stigma has also been reported to cause psychological stress for people with Tuberculosis ⁽⁹⁾. The Stigma in the community towards tuberculosis sufferers is due to their fear of infection from tuberculosis disease and lack of information and

knowledge related to the disease ⁽¹⁰⁾.

The negative Stigma from the community towards Tuberculosis is also still happening in Aceh. This condition can delay handling tuberculosis cases, especially in people with high customs and culture such as Simeulue Regency. As a district with many tuberculosis cases in Aceh, programs run by the government regarding tuberculosis cases still focus on the treatment process and discoveries compared to prevention and social support. Important health promotion efforts are given to the community to increase knowledge, awareness, and community support for people with Tuberculosis. Several studies say that there is still a negative stigma in Tuberculosis patients ⁽¹¹⁻¹⁵⁾. Ariyanti, in her study, stated that 81.9% of Tuberculosis patients experienced Stigma. As many as 50.4% of Tuberculosis patients experienced Stigma in the form of feelings of worthlessness, shame, fear, hopelessness, guilt, and loss of self-esteem ⁽¹⁴⁾.

Negative societal Stigma in patients with Tuberculosis can cause sufferers and their families to cover up their cases often and refuse to get health services. Therefore, this study aims to analyze the relationship between knowledge, perception, psychological and socio-cultural factors, and the Stigma of tuberculosis sufferers in Simeulue Regency.

Method

This research was quantitative with a cross-sectional study. This research was conducted in Simeulue Regency from January 25 to March 2021, precisely in the working areas of the East Simeulue Health Center, Salang Health Center, Teluk Dalam Health Center, Alafan Health Center, and West Simeulue Health Center. The study population was tuberculosis sufferers, totaling 112 people in 10 sub-districts in Simeulue Regency. The sample was

determined using a purposive technique with 92 families of Tuberculosis patients with the inclusion criteria: 1) Men and women aged 17-65+, 2) Tuberculosis patients or families with Tuberculosis Patients, 3) Not in treatment, and 4) Willing to be respondents.

The research instrument was a questionnaire consisting of respondents' demographics, knowledge, perceptions, psychological factors, and socio-cultural which were adopted from Astuti's study ⁽¹⁶⁾. Knowledge variable is categorized as good if $x \geq 75$, sufficient if $x = 56-74$, and less if $x < 55$. Perception is categorized as positive if $x > 6.5$, and negative if $x < 6.5$. Psychological factors are categorized as good if $x > 2.5$ and less $x < 2.5$. Socio-cultural factors are categorized if $x > 2.5$ and less if $x < 2.5$. The value of Stigma against tuberculosis sufferers in this study used an instrument developed by "The United States Agency for International Development/USAID, 2018) and categorized as good and bad categories.

All instruments used have been tested for validity and reliability and are declared valid and reliable. This study has passed the ethical test and received approval from the Research Ethics Committee of the Faculty of Nursing, Syiah Kuala University, with research code 112017101220. Lastly, to determine the relationship between variables, the analysis was carried out using the Chi-Square test with a significance level (α) 0, 05.

Result

This research was conducted in January-March 2021, and data were collected from 92 respondents. The characteristics of the respondents consist of age, gender, employment status, education, income, and History of smoking history.

Table 1: Respondent Characteristic (N:92)

Characteristics	Frequency (f)	Percentage (%)
Age		
26-35	9	9,8
36-45	43	46,7
46-55	21	22,8
56-65	13	14,1
65 +	6	6,5
Gender		
Male	38	41,3
Female	54	58,7
Employment Status		
Not working	22	23,9
Entrepreneur/Farmer/Trader	63	67,4
Civil Servant	7	8,7
Education		
No school	5	0,4
Elementary School	36	39,1
Junior High School	22	23,9
Senior High School	34	36,9
College	8	8,7
Income		
High > 1.700.000	11	12,0
Low < 1.700.000	81	88,0
History of Smoking		
Yes	69	75,0
No	23	25,0

Table 1 shows that the majority of respondents are 36-45 years old (46.7%), female 54 people (58.7%), employment status are entrepreneurs/farmers/traders as many as 63 people (67.4%), low income are 81 people (88.0%), and no history of smoking as many as 79 people (85.9%).

The results of research on knowledge, perceptions, psychological factors, and socio-cultural respondents related to Tuberculosis can be seen in the following table:

Table 2: Knowledge, Perception, Psychological, Socio-Cultural, and Stigma Factors of Respondents on Tuberculosis Patients in Simeulue Regency (N:92)

Indicator	Frequency (f)	Percentage (%)
Knowledge		
Good	66	71,7
Sufficient	18	19,6
Less	8	8,7
Perception		
Positive	79	85,9
Negative	13	14,1
Psychological Factor		
Good	75	81,5
Less	17	18,5
Socio-cultural		
Good	61	66,3%
Less	31	33,7%
Stigma		
Good	34	37%
Bad	58	63%

As presented in Table 2, the study results show that the respondents' knowledge about Tuberculosis is in a good category (71.7%). From the perception side, it is known that the respondents' perceptions are in the positive perception category (85.9%), and from the psychological side, they are in a good category (81.5%). At the same time, the socio-cultural aspects are in a good category too (66.3%). However, Table

2 also shows that most respondents have a bad stigma towards TB sufferers (63%).

The results of research on the relationship between independent variables consisting of aspects of knowledge, perception, psychological factors, and socio-culture with the dependent variable, namely Stigma in Tuberculosis sufferers, are presented in the following table:

Table 3: The relationship between knowledge, perception, psychological factors, and socio-culture with Stigma in Tuberculosis sufferers in Simeulue Regency

Indicators	Stigma in Tuberculosis Sufferers				Total		
	Good		Bad		f	%	P-value*
	f	%	f	%			
Knowledge							
Good	31	24.4	35	41.6	66	100	0.007
Sufficient	2	6.7	16	11.3	18	100	
Less	1	3.0	7	5.0	8	100	
Perception							
Positive	33	41.8	46	58.2	79	100	0.027
Negative	1	7.7	12	92.3	13	100	
Psychological Aspect							
Good	32	42.7	43	57.3	75	100	0.035
Less	2	11.8	15	88.2	17	100	
Social Aspect							
Good	29	47.5	32	52,5	61	100	0.006
Less	5	16,1	26	83,9	31	100	

* *Chi-Square Test*

As presented in table 3, the study results show that 35 (41.6%) respondents with good knowledge have a bad stigma on tuberculosis sufferers. The chi-square test results obtained a P-value of 0.007 <0.05, meaning that there is a relationship between knowledge and Stigma in patients with Tuberculosis. The chi-square test showed a p-value of 0.027 <0.05, which means a relationship between perception and Stigma in patients with Tuberculosis. Then, the results of the chi-square test were obtained with a p-value of 0.035 <0.05, which means that there is a relationship between psychological factors and Stigma in Tuberculosis patients. Likewise, with the socio-cultural aspect with a p-value of 0.006 <0.05, there is a socio-cultural relationship with Stigma in Tuberculosis patients. In this study, the most dominant sub-variable associated with Stigma was socio-cultural, with a p-value of 0.006 <0.05.

Discussion

This study showed that 31 (24.4%) respondents had good knowledge of Tuberculosis and had a good stigma on Tuberculosis sufferers. However, there are 35 (41.6%) respondents with good knowledge, had a bad stigma on Tuberculosis sufferers. In this case, even though the respondents have good knowledge, they still have a bad stigma for Tuberculosis sufferers. That condition because Tuberculosis is still a disease that is feared in society, it is easy to transmit to other people and is still considered an awful disease. It means the Stigma in society is still bad for people with Tuberculosis sufferers. It is in accordance with the results of previous studies, which showed that the community had a high stigma (45.5%) against tuberculosis sufferers and stated that people with Tuberculosis is deserved to be rejected by the community (37.8%). In addition, they also think that they will have bad effects if they are close to

tuberculosis sufferers (93.3%) This condition shows that not all respondents with good knowledge and higher education have good behavior towards people with Tuberculosis. Sandha & Sari stated it happened because the good knowledge of Tuberculosis can raise concerns about the disease, especially because of its transmission ⁽¹⁶⁾.

In terms of perception, this study found that 33 (41.8%) respondents had a positive perception of Tuberculosis and had a good stigma on Tuberculosis sufferers. Perception is a process preceded by sensing, a stimulus received by the individual through a receptor ⁽¹⁷⁾. The results of previous research on public perceptions about Tuberculosis found that 61.2% of respondents had positive perceptions, and 38.8% had negative perceptions about Tuberculosis. The most dominant factor influencing public perception is education.

In psychological factors, it was found that as many as 32 (42.7%) respondents had a good stigma on Tuberculosis sufferers, and 43 (57.3%) respondents had a bad stigma on Tuberculosis sufferers. This study also found that although the psychological factors were good, the Stigma about tuberculosis sufferers remained bad. It is In line with a study by Cremers et al. in 2015, which stated that as many as 80% of Tuberculosis respondents experienced Stigma, and some of them (50.4%) experienced self-stigma in the form of feelings of worthlessness, shame, fear, hopelessness, guilt, and loss of self-esteem ⁽¹⁸⁾.

In the socio-cultural aspect, the results showed 29 (47.5%) respondents socio-cultural in the good category and had a good stigma on Tuberculosis sufferers. However, there are 32 (38.5%) respondents with a good socio-cultural have a bad stigma on Tuberculosis sufferers. A total of 5 (16.1%). The chi-

square test results obtained a p-value of 0.006 <0.05, meaning a socio-cultural relationship with Stigma in patients with Tuberculosis.

Related to the Stigma of people with Tuberculosis, Courtwright & Turner ⁽¹⁹⁾, said that in addition to increasing knowledge about Tuberculosis, the important thing in reducing Stigma is to provide support to people who are stigmatized. The support given to the patient becomes one of the important things considering that Stigma is also related to the values and attitudes of the individual concerned. Society's view of Stigma reflects culture as an accumulation of beliefs, and Stigma is a belief or view of certain characteristics and characteristics of a group or individual that is unwanted. When someone knows that a friend, neighbor, or even family suffers from Tuberculosis, he will treat those others differently, such as not wanting to be close or talking ⁽²⁰⁾.

Aryani, in his research, shows that the Stigma of Tuberculosis in society is still negative, and some people think that tuberculosis sufferers are disgusting and agree not to let tuberculosis sufferers live in society ⁽²¹⁾. The negative Stigma in society causes some people to be ashamed to check their health or illness to health services and tend to choose traditional medicine. This condition has a negative effect on patients with Tuberculosis because Stigma is related to disease harms prevention, service procedures, and policies related to health. Different perspectives related to Stigma in tuberculosis sufferers can lead to various attitudes towards tuberculosis treatment ⁽²²⁾. Therefore, it is necessary to socialize the community in understanding by providing understanding and knowledge of the correct concept of Tuberculosis, how it is transmitted. Both patients and the community can know better to keep themselves from being infected

but still appreciate Tuberculosis sufferers and support them until they feel better.

Conclusion

This study concludes that knowledge, perception, psychological factor, and socio-culture aspect significantly correlate with Stigma in patients with Tuberculosis in Simeulue Regency. The socio-cultural aspect is the most dominant sub-variable associated with Stigma with a p-value of 0.006 <0.05. In general, the respondents' knowledge, perception, psychology, and socio-cultural aspects about Tuberculosis in Simeulue Regency are in the positive and good categories. However, the majority of respondents have a bad stigma against Tuberculosis sufferers (63%).

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