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# Factors that Influence the Formation of Public Stigma Towards Leprosy Sufferers in East Kolaka Regency

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### ABSTRACT

**Introduction:** Leprosy can cause health problems in the form of permanent disability. Disability due to leprosy is not only physical which has an impact on daily activities and social participation, but also economic and psychological. The stigma of society towards leprosy sufferers can cause negative feelings of leprosy sufferers such as being embarrassed to socialize with the surrounding community to isolating themselves. The purpose of this study was to see the factors that influence the formation of public stigma towards leprosy sufferers in East Kolaka Regency.

**Method:** This study uses a qualitative descriptive approach with an exploratory research type by conducting direct observation and in-depth interviews. The subjects were all people in Ladongi District and Aere District, East Kolaka Regency, the determination of informants in this study was carried out through purposive sampling techniques.

**Result:** Factors that influence the stigma of society towards leprosy in Kolaka Regency occur due to the lack of public knowledge regarding leprosy, the existence of a culture and tradition of society that avoids or even labels leprosy sufferers with negative things, public concerns about the transmission of leprosy when they are close to or live side by side with leprosy sufferers, and the influence of religion and community beliefs that consider leprosy sufferers as a punishment from God for the sins they have committed.

**Conclusion:** Leprosy sufferers need support from the community and family, so that they have the confidence to undergo treatment, thereby reducing the prevalence of leprosy in East Kolaka Regency.

### Introduction

Leprosy is one of the eight neglected tropical diseases (NTDs) that are still found in

Indonesia.<sup>[1]</sup> Leprosy that is not treated immediately will cause the disease to develop progressively, causing damage to the skin, nerves,

limbs and eyes, and can then further cause disability in sufferers.<sup>[2]</sup> Leprosy is a type of infectious disease that is still a health problem in the world, including Indonesia.<sup>[3]</sup> Leprosy has a wide impact on the lives of sufferers, not only in terms of health, which can cause permanent disability, but also causes problems in marriage, work, interpersonal relationships, business activities, and even their attendance at religious events and events in the community.<sup>[4]</sup>

Leprosy can cause health problems in the form of permanent disability.<sup>[5]</sup> Disability due to leprosy is not only physical, which impacts daily activities and social participation, but also economic and psychological.<sup>[6]</sup> Leprosy disability occurs due to impaired nerve function in the eyes, hands and feet. The longer the time from the first time early signs are found until treatment begins, the greater the risk of disability due to progressive nerve damage.<sup>[7]</sup>

The World Health Organization (WHO) states that more than 200,000 new cases of leprosy are found every year in the world, according to Zuhdan et al, The regions with the highest cases are America (15.3%) and Southeast Asia (72.1%) including Indonesia. Meanwhile, the prevalence rate (level of spread) of leprosy in Indonesia in 2019 was 0.74 cases/10,000 population and the number of new cases found was 6.51 cases per 100,000 population.<sup>[8]</sup>

The International Federation of Anti-Leprosy Associations defines stigma as a negative response to human differences in visible signs or differences in behavior.<sup>[9]</sup> The stigma associated with leprosy stems from socio-cultural beliefs that are often irrational and can hinder all aspects of leprosy control. Patients with leprosy tend to hide their condition and do not seek or comply with treatment for fear of social rejection. As a result, early case detection is hampered, leading to permanent disability.<sup>[10]</sup>

Based on statistical data from the BPS of Southeast Sulawesi in 2021, it shows that in 2020 the number of new leprosy cases in Southeast Sulawesi Province was 165 cases consisting of 31 cases of Pausi Basiler Leprosy (Dry Leprosy) and 134 cases of Multii Basiller Leprosy (Wet Leprosy) with a new case detection rate (New Case Detection Rate/NCDR) per 100,000 population.<sup>[11]</sup>

The stigma of society towards leprosy can be classified into 3 forms<sup>[2]</sup>, namely; first, Enacted stigma or experienced, where leprosy sufferers have experienced discrimination such as rejection by health workers, isolation from family members, or loss of employment or education. Second, Perceived stigma or anticipated stigma or felt stigma, is a stigma that is felt/perceived by leprosy sufferers themselves, and third Self stigma/internalized stigma, a negative social reaction based on the health condition or disease suffered.<sup>[3]</sup>

The study conducted found that in 2020, the number of new leprosy cases in Southeast Sulawesi Province was 165 cases consisting of 31 cases of Pausi Basiler Leprosy (Dry Leprosy) and 134 cases of Multii Basiller Leprosy (Wet Leprosy) with a new case detection rate (New Case Detection Rate or NCDR) per 100,000 population in Southeast Sulawesi Province of 6.29 8.8 lower than in 2019 (165 new cases or NCDR; 11.0). Based on the type of disease, leprosy consists of 2 types, namely dry leprosy (Pausi Basiler/PB) and wet leprosy (Multi Basiler/MB). When viewed based on the type of disease, the Pausi Basiller (PB) type of leprosy was 31 cases and the Multi Basiller (MB) type of leprosy was 134 cases. According to gender, the proportion of Pausi Basiler Leprosy is lower in males (32.26%) than in females (67.74%). In contrast to Multi Bacillary leprosy, it is dominated by males at 62.69% compared to females at 37.31%. The proportion of the two types of leprosy is highest in males at 56.97% and in females at 43.03%.<sup>[14]</sup>

The stigma of society towards leprosy sufferers can cause negative feelings among leprosy sufferers, such as being embarrassed to socialize with the surrounding community and isolating themselves.<sup>[15]</sup> This causes leprosy sufferers to not want to undergo treatment because they are afraid that their disease will be known by the surrounding community and get a negative stigma against them. Unbeknownst to sufferers, this will increase the prevalence (level of transmission) of leprosy to their closest families and the surrounding community.<sup>[16]</sup>

The prevalence of leprosy has continued to decline over the past 5 years. If we look at the prevalence rate of leprosy in 2020 in Southeast Sulawesi Province, it was 0.66 per 10,000 population, lower than in 2019, which was 1 per

10,000 population. There were 14 cases of PB leprosy registered in Southeast Sulawesi Province in 2020 and 250 cases of MB leprosy. Of the 14 total cases of PB leprosy, 12 (86%) cases of leprosy had completed treatment and of the 250 cases of MB leprosy, 193 (77.2%) cases had completed treatment.<sup>16</sup> The number of leprosy cases registered in Southeast Sulawesi Province in 2020 was 165 cases consisting of Pause Bacillary Leprosy and Multi Bacillary Leprosy. West Muna Regency is the Regency with the lowest number of leprosy cases, namely 1 case and Bau-Bau City is the Regency with the number of cases, namely 35 cases, while the incidence of leprosy cases in East Kolaka Regency tended to increase in 2020 by 10 cases while in 2021 it increased by 2 to 12 cases. The high and low leprosy cases are influenced by the characteristics of the leprosy endemic area and the performance of the program in finding cases.<sup>16</sup>

Based on the background description, the researcher is interested in conducting research entitled Factors that Influence the Formation of Public Stigma Towards Leprosy Sufferers in East Kolaka Regency.

## Method

This study uses a qualitative descriptive approach with an exploratory research type by conducting direct observation and in-depth interviews.<sup>17</sup> The subjects were the entire community in Ladongi District and Aere District, Kolaka Regency, consisting of ordinary informants, namely leprosy sufferers and families of leprosy sufferers, while the key informants numbered 20 people. The determination of informants in this study was carried out through purposive sampling techniques.

## Results

In this section, we will describe several factors that influence the formation of stigma and the tendency of society in judging leprosy sufferers in their environment. The factors that influence the formation of public stigma on leprosy sufferers in East Kolaka Regency are as follows;

## Knowledge

In this section, we will describe the public's knowledge about the causes of disease.<sup>18</sup> Community knowledge regarding leprosy can come from their knowledge directly or indirectly.<sup>19</sup> Directly, this knowledge is obtained from formal and non-formal education and can be obtained through direct experience with leprosy sufferers. While indirect knowledge is obtained through the experiences of others known to them.<sup>20</sup> Based on the research results, community knowledge related to leprosy. Based on the research results, knowledge related to leprosy is obtained by the community from religious knowledge sources. As stated by one of the research informants named Alimudin, a religious figure in East Kolaka Regency, who stated that

The first resource person, Mr. Musahudin, a religious figure who is respected by the community, said that:

As for Leprosy itself, I don't know for sure the cause, as told in the time of the Prophet, leprosy was described as a prolonged skin disease and often claimed someone's life. Maybe it was caused by a virus or bacteria and lack of cleanliness. Religion also teaches how to clean yourself according to the prophet's recommendations. Maybe it was also a test from God as an ablution of sins" (interview June 18, 2023)

Based on the results of interviews with research informants, the community knows about leprosy from religious knowledge sources (Muslims), but specifically the community does not know for sure the cause of leprosy, but knows about the type of leprosy as a type of skin disease that has existed since ancient times. In addition, based on religious knowledge sources, leprosy prevention can be done by maintaining cleanliness of the body and environment.

Furthermore, regarding the relationship between religion and leprosy, research informants said that;

*"Leprosy can also be a reprimand from God, because in this life there are many kinds of tests. There are those who are tested with power, position and disease. But sometimes the degree is different. In Islam, it is usually known as 3 stages. Whether it's a test, punishment or istikhraj. If the test is intended to increase the quality of a servant's faith, if the punishment is intended to*

*reprimand the servant, while there is something worse, namely istikhraj, without any problems, sustenance is safe and healthy even though you often sin. That is what is collected for the punishment in the hereafter. Wawlahualam. The point is that God will never give a trial to a servant if it is beyond the servant's ability".* (interview June 18, 2023)

Based on the results of interviews with research informants, representatives of religious figures with religious understanding (Islam) believe that leprosy has existed since the time of the prophet, and is associated with sin or as a result of sin and mistakes made by certain individuals.

In addition, another opinion from the informant, religious figure Mr. Ahmad, expressed his understanding of leprosy:

*"I don't really know what causes leprosy, because I'm not a health major. But from what I've heard, it's said to be caused by bacteria. But I don't know for sure either."* (interview, June 18, 2023)

It appears that there are still many people who know about leprosy only based on physical characteristics, this is similar to the answer given by Mr. Rizal Bakri as a representative of the local government figure who was interviewed by the researcher, he said:

*"If I'm not mistaken, leprosy is a contagious disease. This disease is caused by bacteria, but I don't know the exact name of the bacteria and what causes it. Leprosy is like itching all over the body and not just an ordinary skin disease. I've seen people with leprosy whose nerves died and their limbs became stiff."* (interview June 21, 2023)

Based on this, public knowledge regarding leprosy mostly assumes it as a skin disease that is long-term in nature. This can also be seen in the next informant. Hj. Fatma as one of the informants when interviewed about leprosy, stated that:

*"If you've heard of the name of the disease and seen it, it's like curse, who has an itchy skin disease for years. The cause may be due to poor hygiene or rarely cleaning yourself properly, such as coming home from a crowded place or something like that but not immediately cleaning yourself like taking a shower when you get home (Maybe)"* (Interview, June 23, 2023)

In this case, it can be seen that the public's understanding of leprosy is only limited to

assessing physical characteristics. This is different from the answers from families of leprosy sufferers who have received health education from health center officers. As told by Mrs. Putu Ratnasari, she said:

*"As explained by the health center officer, he said it was because of bacteria, not because of magic or the like. He said it was transmitted. Initially, \*\*\*\* contracted leprosy after returning from traveling to Morowali in 2016, maybe he lived there in the same place, in one place, eating and drinking utensils were the same. At first, we also thought this was just an ordinary skin disease, but over time it spread and started to become numb. After further examination, we were just told that this was leprosy, at first, we didn't know what leprosy was, later after further explanation we found out. Finally, at that time our whole family was examined because they were worried that we had been infected. And we were also given medicine that had to be taken for some time until it was confirmed that we were safe and not positive for leprosy."* (Interview June 27, 2023)

Furthermore, the research informant, Siti Mujaena, who works at the Ladongi health center, said that:

*"Leprosy is a skin disease, but unlike skin diseases in general that can be cured with only light treatment. Leprosy is caused by bacteria that inhabit the sufferer's body and not only the skin actually, but also to the point of killing the sufferer's nerves. That's why sometimes when we see sufferers who cannot be treated, their fingers seem stiff and dead, they can no longer be moved. That's because of leprosy. It's just that lay people often ignore this disease because basically the initial symptoms are not visible. Moreover, in theory, leprosy takes 5 years to incubate in the human body until it shows symptoms. So, if the treatment that has already appeared symptoms is actually too late, therefore in the health center there is something called a program for preventing infectious diseases, with us conducting observations and epidemiological tracking of vulnerable or high-risk community groups such as the sufferer's family or closest people. Because if leprosy has become severe and kills nerves, even if it is cured, the nerves that have died will become permanently disabled."* (Interview June 23 2023)

Based on the description of the interview results with informants, we can see that knowledge

is a factor that can influence the formation of a stigma. Due to the lack of knowledge about leprosy, people assume personally based on their respective empirical experiences and most of the informants interviewed said that leprosy is considered a prolonged skin disease, some informants who are considered religious people also explained their understanding of the causality of leprosy as a reprimand from God.

From the informants that researchers have interviewed, there are still those who do not know the true meaning of leprosy, because they only know leprosy based on the physical disabilities suffered by leprosy sufferers. Public knowledge about the causes of leprosy varies, according to them that the cause is from germs, bacteria, viruses, because they rarely bathe, do not maintain personal hygiene, and an unclean environment and there are even those who consider leprosy as something mystical.

### **Trust**

The stigma of stigmatized diseases is also formed by a person's religious understanding, where the informants interviewed among others gave answers related to leprosy from a religious perspective and beliefs that are still related to mysticism. This can be seen from the results of interviews conducted by researchers with religious figures by Mr. Sodiram, he said:

*"Leprosy can also be a reprimand from God, because in this life there can be many kinds of tests" besides that, people's beliefs are also still in contrast to beliefs about magic, they think that leprosy itself is related to magic.*" (Interview, July 3, 2023)

As stated by one of the informants, a relative of a leprosy sufferer, Sohrawati, who was interviewed by the informant, said that:

*"There are even those who say that this is black magic or sent by other people. There are still people here who believe that leprosy itself is closely related to mystical things, just like tuberculosis which people think is caused by exposure to poison, we call it bajabo"* (Interview, July 3, 2023).

So based on that, the stigma of society regarding leprosy sufferers is also influenced by religion and beliefs about naive things that are mystical in nature. Because of the formation of culture and hereditary paradigms in a society when conceptualizing the cause and effect of a

phenomenon, it produces views or judgments that are still mystical in nature. It can be seen when several informants said that leprosy is considered as magic.

## **Discussion**

### **Factors Influencing Stigma**

There are several factors that influence a stigma against leprosy sufferers in East Kolaka Regency. Some of these factors include:

#### **Lack of Knowledge**

If people do not have enough understanding about a group or condition, they may tend to develop prejudice or misconceptions about it. Lack of knowledge can have a major impact on shaping and reinforcing the stigma that people have towards people with leprosy. Here are some ways in which lack of knowledge influences the stigma towards people with leprosy:

#### **Conceptualizing About Transmission**

Lack of knowledge about how leprosy is transmitted can lead to the mistaken belief that the disease is highly contagious. This can result in isolation and exclusion of people with leprosy. As seen in the phenomenon in East Kolaka Regency, due to lack of knowledge, people tend to keep an excessive distance because they assume that people with leprosy who are undergoing treatment can transmit the disease very easily.

#### **Inaccurate Understanding**

Without proper knowledge about leprosy, people may have an inaccurate understanding of the symptoms, treatment, and prognosis of the disease. This can trigger prejudice and fear.

#### **Association with curses or punishment**

Lack of medical knowledge can cause people to associate leprosy with a curse or divine punishment. This can create negative views and stigma towards people with leprosy.

#### **Culture and Tradition**

Certain cultural norms and traditions can shape how society views certain groups. If the culture has certain assumptions or prejudices, stigma can form. Culture and tradition can have a strong influence in shaping views and stigma

towards people with leprosy. Here are some ways in which culture and tradition can influence the stigma towards people with leprosy.

### **Concept of Purity and Cleanliness**

Culture and tradition often emphasize the importance of purity and cleanliness. If people with leprosy are considered "unclean" or "impure", this can trigger stigma and exclusion of them. This is evident from several informants who when interviewed said that leprosy was caused by a lack of maintaining personal hygiene.

### **Historical Stigma**

If a culture has a history of stigma against a particular disease, this negative view can be inherited and continue to this day. As in the culture of East Kolaka Regency where a skin disease is always considered as something disgusting and is often considered dirty because of the inability to care for oneself.

### **The Importance of Self Image and Social Image**

Culture and tradition often influence how individuals see themselves and how they want to be seen by society. If leprosy sufferers feel their image is threatened, they may experience stress and isolation, this can be seen from the confessions of the patient's family when interviewed, the family said that even the leprosy patient himself stopped taking medication because he was desperate and no longer had the motivation to recover and tended to withdraw from the social environment.

### **Influence of Parents and Family**

Culture and traditions in the family environment can influence views on leprosy sufferers. If the family or parents have negative views, this can strengthen the stigma. This can be seen from the interview results. There were informants who said that close families of leprosy sufferers were shunned by their own relatives.

### **Worries and Fears**

Worries and fears can have a significant impact in shaping and reinforcing stigma against people with leprosy. Here are some ways in which worries and fears can influence stigma:

### **Association with Threats**

Worries and fears about leprosy can make people consider sufferers as a potential threat to their own health and safety. Based on the results of interviews and observations, researchers said that

the surrounding community who live in the same environment as leprosy sufferers in East Kolaka Regency themselves consider that their fear of the potential for infection is the same as their fear during the Covid pandemic in 2019.

### **Social Separation**

Fear of contracting leprosy can drive people away from people with leprosy, creating social isolation that reinforces the stigma. This can also be seen based on the statements of informants who said they still maintain friendships but not as close as before because of the fear of contracting leprosy from the sufferer.

### **Religion and Belief**

Religion and beliefs can play an important role in shaping views and stigma towards people with leprosy. Some of the ways in which religion and beliefs can influence stigma towards people with leprosy include:

### **Theological Interpretation**

In some religious traditions, illness or suffering is often interpreted as a punishment or test from God. If leprosy is considered a divine punishment, this can cause stigma because people with leprosy are considered to have done something wrong. This is emphasized by the statement of one informant who said that in his belief leprosy is a rebuke from God for a sin that the sufferer may have committed in the past.

### **Historical Stigma**

In some beliefs, infectious diseases such as leprosy can be considered to carry "negative energy" or "evil spirits". As a result, people with leprosy can be isolated or exiled from the community so that the "energy" or "spirit" does not spread. This can be confirmed by the narrative of the family of a leprosy patient who said that at first, they carried out traditional treatment because they believed in their beliefs that the leprosy suffered by their family members was caused by supernatural or mystical things.

### **Conclusion**

Factors that influence the stigma of society towards leprosy in Kolaka Regency occur due to the lack of public knowledge regarding leprosy, the existence of a culture and tradition of society that avoids or even labels leprosy sufferers with

negative things, public concerns about the transmission of leprosy when they are close to or live side by side with leprosy sufferers, and the influence of religion and community beliefs that consider leprosy sufferers as punishment from God for the sins they have committed.

Leprosy sufferers need support from the community and family, so that they have the confidence to undergo treatment, thereby reducing the prevalence of leprosy in East Kolaka Regency.

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