

## Profile Stigma of Leprosy Patients in Manokwari District Provinsi Papua Barat

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### ABSTRACT

**Background:** A person who has leprosy experiences stigma from himself, family and society. Stigma for people affected by leprosy about diseases, ease of possible disease, the severity of disease, the benefits of positive behavior and the risk of negative behavior and treatment of leprosy.

**Objective:** To find out the stigma profile of lepers in Manokwari Regency, West Papua Province.

**Research Methods:** Qualitatively conducted at the Pasir Putih Community Health Center and Amban Community Health Center in November 2018 as many as 6 informants. Data obtained using in-depth interviews and analyzed qualitatively.

**Results:** Stigma of perceptions of informants about leprosy experienced psychopathic disorders such as crying, fear and shame. The informant's perception of leprosy risks transmitting to his family because he lives at home. The severity of leprosy is from the informant's response because it causes disability, paralysis, difficulty eating and drinking and considers leprosy as a savage disease because it can attack suddenly. The benefits of positive behavior from because they do not want to be deformed or disabled that continue or transmit this disease to other families. The risk perception of negative behavior of lepers states that it can cause disability and shame for life. Stigma towards faster treatment will be better for preventing disability. In addition, the informant acknowledged that it was too late for treatment because he did not know about leprosy. One of the reasons for the treatment expressed by the informants was because they wanted to recover

quickly and did not want to get stigmatized from the family or from other people. One of the reasons informants from family stigma is fear of being avoided by the family so they feel isolated from their own family.

**Keywords:** Stigma, Leprosy patient, Transmission risks and Sudden attack.

### INTRODUCTION

Leprosy is a disease that is feared by the public and family. At that time there was spontaneous isolation because the sufferer felt inferior and ashamed (stigma). Besides that people stay away because they feel disgusted and afraid this is due to a lack of knowledge or understanding as well as mistaken beliefs about disease leprosy. Many people still think that leprosy is caused by curses, uses, sins, food or offspring. In this modern era the term "stigmatization" appeared which reflected more "class" than physical. It is this process which ultimately makes the sufferers isolated from society, considered disgusting and must be shunned. Actually this stigma arises because of a perception of a disease that is wrong (Putri, 2016).

Surveys conducted by health ministries in five regencies in Indonesia (Subang, Malang, Gresik, Gowa, and Bone Districts) portray the discrimination experienced by leprosy sufferers both in the family environment, as well as in public facilities and services, such as being separated from spouses (divorced), issued or not accepted at work, rejected in schools,

restaurants, places of worship, health services and other public facilities (Ministry of Health, 2015). Stigma and discrimination often inhibit the discovery of cases of leprosy early, treatment of patients, and handling medical problems experienced by sufferers and people who have had leprosy. Therefore, in an effort to eliminate stigma and discrimination, strong motivation and commitment are needed from both sufferers and the community. Patients are expected to change their mindset, so they can be empowered to help themselves, even others. In addition, the community is also expected to be able to change their views and help sufferers and people affected by leprosy (OYPMK) to stay healthy and be able to maintain health independently (RI Ministry of Health, 2015).

Data on leprosy sufferers in Manowakri District, new leprosy cases reported in 2017 with a total of 265 or a prevalence rate of 15.56 percent. The new Multi Basiler case (MB) 64 percent, new cases in children 36 percent and level 2 defects as much as 3 percent. The incidence of leprosy defects in Manowkari District was 2%. Data on leprosy patients at Pasir Putih Community Health Center were 16 people and Amban Community Health Center were 21 people (District Health Office of Manokwari District, 2018). Based on the preliminary study conducted by the researchers found some behaviors of leprosy patients who were treated at the Pasir Putih Health Center and Amban Health Center were different from those of other diseases. Lepers who are waiting their turn for treatment are often seen behind, using long-sleeved shirts or jackets and hats to cover their hands and feet that have white or red spots that people might see. Lepers are more silent and rarely communicate with people around them. Interviews of 3 people with leprosy who suffered from level 2 disability said he often shunned his family, friends, and even other people when he saw the condition of his hand, so he felt embarrassed and even hurt by the treatment received from other people and even his family.

Based on this, the researcher was interested in conducting a study entitled "Stigma Profile of Leprosy Patients in Manookwari Regency, West Papua Province"

## **MATERIALS AND METHODS**

### **2.1 Type of Research**

This type of research is qualitative descriptive research. Syaodih (2008) states that descriptive research is the most basic form of research. Aimed at natural or human engineering conditions. According to Syaodih (2008) in Pongtiku, (2016) that qualitative research is a study aimed at describing and analyzing phenomena, events, social activities, attitudes, beliefs, perceptions, thoughts of individuals as well as groups. This type of research is qualitative with a case study approach, which is a method of research conducted with the aim of describing the problem that occurs to conclude the image objectively (Swarjana, 2013).

Focus on research to understand the stigma of lepers in Manokwari District, West Papua Province who describe the respondent's characteristics, stigma about leprosy according to respondents' perceptions, ease of possible illness, disease severity, benefits of positive and negative behavior and treatment of leprosy.

### **2.2. Place and Time of Research**

#### **a. Research Place**

This research was conducted at the Pasir Putih Community Health Center and Amban Community Health Center, Manokwari Regency, West Papua Province.

#### **b. Research Time**

This research was conducted in November 2018.

#### **c. Informant**

The selection of informants is done by using a snowball sampling technique, namely the selection of sampling based on the involvement of informants who know the problem clearly, can be trusted to be a good source of data and able to express opinions well and correctly (Swarjana, 2013). Informants were sources of information who

suffered from leprosy and felt a stigma from themselves and the community, namely the leprosy recipient at the Pasir Putih Community Health Center as many as 3 people and Amban Puskesmas as many as 3 people.

## RESULTS

The informants in this study were 6 people aged between 27 - 42 years, of which 3 were male and 3 were female. All informants came from the Papuan tribe, where 3 people worked as farmers and 3 people did not work or as housewives. Long suffered from leprosy between 6 months to 2 years. The general description of the respondents shows that the respondents were early adulthood (26-35 years) and middle-aged adults (36-45 years). In this age group the productive period in the lives of respondents. Respondents felt that their daily activities were very disturbed by their appearance due to changes in physical and decreased self-confidence. Education of the majority of respondents had basic education, ie no school 1 person, elementary school 2 people and junior high school 2 people, while 1 person had a high school education. Respondents who did not work partially were women, some housewives who took care of all their household activities.

Leprosy has a broad influence on the lives of sufferers, ranging from family, work, personal relationships, and interaction with the social environment. Most of the respondents had suffered from leprosy between 6 months to 2 years, in a long period of time the respondent had to always take medication and take medication regularly, if until late in treatment the respondent stated that the disease would reappear.

### **3.1. Stigma about Leprosy According to Respondent's Perception**

Stigma is one of the factors delaying the handling of leprosy which makes people feel embarrassed and late in seeking treatment so that they have experienced disability which results in a decrease in

quality of life. Based on the results of interviews with respondents as a quote from the following interview results:

"When I first got this disease, I felt that there was only a skin disease like phlegm and I just let it go, then there were families asking to check into the puskesmas at that time and I went there they said they had leprosy, it was a fear and shame once, where you have a wound, you don't have to be afraid - don't get cut into pieces, (Informant 1)

When I first checked into the puskesmas because of itching and skin pain, I felt rich in wounds, I said I had leprosy, I felt crying, why did I get sick, what would the family say, so after I returned I didn't tell anyone - the person in the house is still as usual, I'm afraid the family will be afraid of me (Informant 2) When I told you about leprosy, I was afraid because I was late for treatment, my hand was crooked like this, I think the leprosy had a cure but the clerk told me that I could recover, but for disability because of being late this disability could cured (Informant 3)

Sa regret that it's too late to go to the puskesmas to check, I feel leprosy if I get medical treatment, it's not like this, I think this disease is a kind of curse for me, kind of someone who uses it - so I got sick like this (Informant 4) I think this disease is very embarrassing, fortunately you are fast treatment, so you get disabled. if my disability is shy all my life, how can I not be ashamed if people see us with hand or leg defects (Informant 5). I know that I got this disease from where I arrived - suddenly my hand had an agatal race and wounded and was quick to go to the puskesmas at that time, so it wasn't too late. this kind of illness is very embarrassing if there is a family or other people near us, but thankfully you are fast taking medication and taking a routine treatment (Informant 6)

Based on the results of the interview it was concluded that the stigma of the perception of informants about leprosy generally all said shame. Rasamalu is caused due to ignorance of respondents

about leprosy. After being diagnosed with psychopathic leprosy to informants, the dinat cry and fear. Informants who cry and fear because they think this disease is very frightening can even cause or be excluded from family and the environment.

Shyness and fear of the informant occurred expressed by the informant because he was late in conducting a search for help or treatment where two people had experienced disability. Leprosy prevention in Indonesia aims to reduce the burden of leprosy by reducing the transmission of disease, preventing disability in all new sufferers found through proper treatment and treatment, and eliminating social stigma in the community (Ministry of Health, 2011). This is in line with the WHO Strategy in dealing with leprosy, namely by creating quality services for leprosy patients and reducing the burden of leprosy that is carried out not only by early detection of cases but also by reducing disability, stigma and discrimination, and social and economic rehabilitation for leprosy patients (WHO, 2017). Surveys conducted by health ministries in five regencies in Indonesia (Subang, Malang, Gresik, Gowa and Bone) from 959 people portrayed the discrimination experienced by lepers in the family environment, as well as in public facilities and services, such as being separated from spouses (divorced), excluded or not received at work, rejected in schools, restaurants, places of worship, health services and other public facilities (Ministry of Health, 2015).

The perception of stigma felt by the information after being diagnosed with leprosy includes shame, fear of family exclusion, fear, curse disease and use - use. Stigma is a very discrediting attribute. Someone who gets stigma is someone who is not accepted and does not get respect, rights and acceptance from the community or someone who is not socially accepted (Goffman (1963) in Wong (2004). (Brakel, 2003) states that stigma consists of two parts, namely enacted stigma and felt / perceived stigma Enacted stigma is stigma

obtained from outside the patient, while felt/ perceived stigma is stigma that comes from within the sufferer.

The stigma against leprosy in the community makes the sufferer delay / avoids treatment until later there is disability and unproductive so that it further affects the quality of life of the patient. Stigma is still the main factor that causes patients to delay seeking treatment.

The results of the interview were self-stigmatizing after being diagnosed with leprosy. Reasons for respondents delaying treatment because they do not know the initial signs of symptoms of leprosy. The stigma felt was also personal, as well as the stigma he would receive from his family and surrounding environment, especially to informants who had experienced disability because they would bear the shame of their lives because of their disability. According to Heijender (2004) in Rahayuningsih (2012) Stigma can be interpreted as an identity lost because of someone stigma can cause a loss of true identity. A person who is labelled leprosy will usually get negative consequences from his social environment, both for himself and for his family. Stigma can make a person not respected in his social environment or make the individual lower in status in society. The stigma against leprosy will dominate the perceptions that exist in the community about leprosy and how they must treat someone who is labelled leprosy in the community.

Based on the statement of the informant above, leprosy is a disease that creates a sense of stigma from oneself and the stigma felt by the social environment. This research is in line with previous research conducted by Putri (2016) in lepers who are in the Work Area of Balerejo Health Center, Madiun Regency, that leprosy sufferers feel a negative stigma against leprosy not only against affected individuals but also their family members. Negative impressions received by leprosy clients last a lifetime live even after the client is cured. Leprosy clients are treated

like exiles in the community because leprosy is considered a frightening disease or in other words disgusting and embarrassing. The patient's stigma and community stigma make leprosy clients not in a position to carry out the obligations and obligations they expect in their social and family environments. Stigma in leprosy clients like this certainly affects the understanding of disease and self-acceptance of leprosy clients (Princess, 2016).

The informant's income stated that leprosy is a disease that is closely related to negative views and discrimination, both those that arise from within themselves and from society. Stigma is an inherent predicate, undesirable (social and physical) distinction that degrades and discredits a person to be fully accepted in society.

### 3.2. Ease of problems with disease

Although the method of entering *M. leprae* into the body is uncertain, some studies of germs can enter through the skin which allows cold-temperature body parts and through the nasal mucosa. Transmission that occurs *M. Leprae* which is intact (live) out of the patient's body and enters the body of another person. Ways of Transmission of Leprosy In general, this transmission can occur by prolonged contact with patients. Patients who have taken medication according to the WHO regimen do not become a source of transmission for others (Ministry of Health, 2012). Based on the results of interviews with informants about facilitating leprosy, the following interview can be given.

Because I often work in the garden, sometimes I wash my hands at times or if there is air there, it might be affected by leprosy, this disease can also spread to people, so it's separate if you use your own items, towels a place to eat, for fear of being contagious to a family (Informant 1). This disease can be infectious, especially if there are people affected by leprosy around us especially in the family members who are sick, there is no one in the family who is

sick, but maybe infected if you greet yourself, we usually shake hands with our new people and immediately hand, or maybe also when you are working, because farmers are not likely to hold it - hold it dirty, wash it in water that is dirty too bad maybe may be if you sweat it makes you leprosy fast (Informant 2)

Initially I felt itchy, but there is usually a sense of dishwashing, so you think it's just normal, it's not leprosy, you know it's a disease, even though nobody's family has leprosy, there is neighbor who has leprosy, but lives far ahead (Informant 3)

This disease is very easy to infect people, this is just the tragedy that is sick in the family why you can get it, so be careful in your home, don't let someone love to spread to other people or family (Informant 4) maybe it's time to go to the market because you have this disease. This disease if late for treatment makes the defect make you feel embarrassed again, how embarrassed, people see - we see your hands or face if you are disabled (Informant 5)

Maybe it was hit by the people around because it was deliberately possible that he might get a leather, especially if he was shaking hands, maybe that was what made him suffer, especially if we washed our hands (Informant 6) The results of interviews with informants concluded that the ease of getting leprosy, namely three informants stated that work in the garden was dirty, sweating and washing hands in dirty water. In addition, two informants said that the transmission was not known with certainty and suspected the cause was when interacting with people around him such as shaking hands so that skin contact was likely to be affected by leprosy and one informant said that leprosy was suffered because he often went to the market and interacted with other people who transmit leprosy.

Leprosy is more common in sufferers with low socio-economic conditions (Wong, 2004). Social and economic conditions are one of the factors that influence transmission of leprosy

(Kosasih, 2013). Based on the results of the research by Nabila (2012) in Kediri Hospital, leprosy patients distributed the types of work of traders and factory workers, while in other studies conducted by Muchtar (2009 in the Skin and Sex Polyclinic of Dr. Wahidin Hospital Sudirohusodo Makassar, the majority of sufferers are farmers and a small proportion are housewives. These differences can be influenced by geographical factors and progress in the development of the city.

Most of the respondents have the perception that leprosy can happen to everyone, some respondents consider that people who are filthy and their condition decreases which can contract leprosy. Leprosy can be transmitted from lepers to others. Most of the respondents did not know how to spread leprosy and some said that the disease was transmitted through the air and one respondent stated that he could contract leprosy if his blood group was the same as the patient, if not the same would not be infected (Soedarjatmi, 2009).

The statement of the informant about the youth being affected by the disease is not known exactly as stated by the Indonesian Ministry of Health (2012), that the place of entry of leprosy germs into the host's body until now has not been confirmed. It is estimated that the method of entry is through the upper respiratory tract and through skin contact that is not intact. Leprosy is a disease caused by germs / bacteria named (mycobacterium Leprae), this leprosy attacks the peripheral nerves of the person to be numb (but if treatment is rapid this can be prevented), leprosy is an infectious disease whose transmission is not easy, because according to research not all humans in the world who can be infected with leprosy, the proof is that we don't know if we have social relationships with other people but don't know if the person is a sufferer leprosy (Kusharnanato, 2013).

### **3.3. The severity of leprosy**

Leprosy is a kind of biological disease, which lately may be more difficult for us to find sufferers around us. However,

the facts prove that this disease still exists so that it remains a problem for all of us. The stigma attached to the sufferer causes this disease to be dual: in addition to biology, it is also social. Leprosy is a disease caused by bacteria, called mycobacterium leprae. This disease attacks the skin and peripheral nerves. Signs, white spots appear on the surface of the skin in various forms, most of which are whitish (like tinea versicolor) areas (Tarigan, 2013). The difference is, these spots don't feel anything, even numb. So, if it is scratched or stabbed to bleed, it won't feel any pain. If this disease is not treated immediately, then germs attack the nerves causing damage. These germs only attack the peripheral nerves, not attacking the brain or spinal cord. The areas most often attacked by germs are the forearm nerves, lower limbs, and face. If it attacks the hand, causes loss of feeling in the palm of the hand, paralysis of the fingers, and is seen as a finger kiting (claw hand), which is the state of the fingers bent inward and cannot be straightened so that it is in a clawed position. If it attacks the legs, causes loss of feeling on the soles of the feet, even the feet become perfect (foot drop), i.e. the ankles cannot be lifted up so that they are easily injured. Likewise, if it attacks the face, there is paralysis of the eyelid muscles so that it is difficult to close the eyes properly (Tarigan, 2013).

Based on the results of interviews with informants about the severity of leprosy as quoted in the following interview below Leprosy is very serious if we quickly check it, the first time it just feels itchy and normal, but when I go to the puskesmas tell me, I just found out that this is a serious illness not just defective, but it can make me swear what about us this life (Informant 1) Leprosy is very dangerous if it is too late to be handled other than that also if not regular treatment can also be disabled (Informant 2)

You just found out, you've also seen a neighbor who is sick like this, but you just know that leprosy is very dangerous, especially if we prevent it - we can get this disease in our family, so this disease is

dangerous so we This must be careful with this disease, which hand is handicapped again, so I feel sorry and too sad with this disease (Informant 3)

This disease can make us even paralyzed, we can walk to eat and drink, we can also have difficulty eating, when I feel my hands and feet are difficult to move, I feel angry at myself why don't I immediately go to a health center (Informant 4)

This disease is very savage when you know where it arrives - when it comes to this disease, even though there are no leprosy in the family, maybe because you keep it clean after interacting with people (Informant 5). This disease is very dangerous, late treatment can be fatal to new disabilities, so you can return to the beginning, which makes people feel embarrassed, everywhere - especially if you talk to people around (Informant 6)

The results of interviews with informants concluded that the severity of leprosy that 3 informants stated that the severity of this disease in addition to causing disability can cause paralysis which has an impact on eating difficulties and makes it difficult to eat and drink. One informant stated that leprosy was a savage disease and one person said he was fortunate because he suddenly attacked. From the statement of the informants two people have experienced disabilities and revealed the danger of this disease. Individual perceptions of the same disease can be perceived differently. The informant perceives as a dangerous disease that suddenly attacks. What is felt by a person can be felt unhealthy for others. In reality, in the community there is a diverse concept of health-sickness that is sometimes not in line even contrary to the concept of healthy-sickness directed by health service providers. This difference in perception can affect individual behavior when sick, which sometimes tends to make their own decisions.

In this study, it was found that the majority of respondents considered leprosy

a dangerous disease and serious reasons for respondents are cystic disease resulting in changes in physical shape and disability where this disability can slow down the lifetime. Most respondents viewed leprosy as a cause of death. It was stated that the symptoms that appeared during this disease were very severe, and when the first time they were treated 2 informants had experienced a disability until the respondents felt very dangerous, while other informants were quick to treat and stated that the disease was very embarrassing. Informants who suffer from leprosy experience disability due to the delay of the person to take the medicine perfectly or the medication is not complete. The delay in the diagnosis of leprosy can result in irreversible nerve damage that ends in permanent disability; this is in accordance with the opinion of Putra (2016) which states that patients who are sick more than 6 months and have just undergone treatment can increase the risk of disability. Early diagnosis and appropriate treatment are very necessary to provide understanding of cases of leprosy to sufferers.

## CONCLUSION

Based on the results of the study concluded as follows:

1. Characteristics of informants aged between 27 - 42 years, 3 men of male sex and 3 people of female sex. All informants came from the Papuan tribe, where 3 people worked as farmers and 3 people did not work or as housewives. Long suffered from leprosy between 6 months to 2 years.
2. Stigma of perceptions of informants about leprosy experiencing psychopathic disorders such as crying, fear and shame.
3. The informant's perception of leprosy risks transmitting to his family because he lives at home.
4. The severity of leprosy from the responses of informants because it causes disability, paralysis, difficulty eating and drinking and considers leprosy as a savage disease because it can attack suddenly.

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