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Phenomenology Study of Self-Efficacy of Leprosy Patients Due to Social Stigma

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Abstract---Background,*Leprosy is a disease with stigmatization that affects the self-efficacy and behavior of sufferers. Social stigma can influence patient behavior in taking care of themselves both in the home and social environment. Self-efficacy oflepers needs to explore further to motivate clients to obtain an even better degree of health through their belief in regular treatment.*

Purpose: *This study aims to explore the experience of self-efficacy level and behavior of lepersdue to social stigma.*

Methods: *This study used qualitative research with a phenomenological approach. Data was collected by using in-depth interviews and group discussion forums on 12 participants in Madura island. This study useda purposive sampling technique and used the principle of immersion, which was positioning themselves as if it was part of the observed phenomenon.*

Results: *This study revealed eight themes, those are the response of lepers, leprosy patients experiencing sadness, leprosy self-image, overview of disease, changes experienced, efforts to overcome problems, hope of lepers, and stigma of leprosy. Lepers had limitations by closing themselves because they are ashamed, afraid, and worried about the people's behavior in their environment.*

Conclusion: *Stigma and discrimination in leprosy coming from the family and community become the main source of triggers for chronic sorrow in lepers and affect the self-efficacy of the sufferers.*

Keywords---*leprosy, self-efficacy, chronic sorrow, stigma*

I. Introduction

Leprosy is one of the oldest diseases that still becomes a major concern in the world of health (1). Although WHO has stated that the prevalence of the disease has been reduced by the presence of multidrug therapy and BCG vaccines, however, the disease is still a scourge in the community at this time(2).The prevalence of leprosy in some regions in Indonesia is still more than 1 per 10,000 population, especially in the regions of eastern Java, Sulawesi, West Papua, and North Maluku. The prevalence rate of leprosy in Indonesia is currently 0.71 per 10,000 population with a total of 18,248 registered cases(3). Leprosy has a wide influence on the lives of sufferers, starting from marriage, work, relationships, to daily activities and events in the surrounding environment (4). There are a number of conditions where lepers suffer from the burden of stigma that develops in the community(5). Some of the developing perceptions in the community related to leprosy include curse, hereditary, incurable diseases, and even illnesses caused by God's trials. This makes lepers even more marginalized by the existence of discrimination that is still very strong in the community(6). Psychological problems for lepers can cause disruption of social interaction in leprosy

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sufferers due to negative views from the community. Lepers anticipate the stigma by hiding their condition, such as avoiding questions related to the disease and lying because of concerns if the disease is known. Feelings of shame and fear can cause anxiety and depression and even reduce social participation (6).

Stigma is a belief about a certain group. Prejudice is a negative or positive evaluation of a particular person or group. Discrimination is behavior directed at a person or group of people based on a certain cause. Discrimination causes exile, difficult to find work, limited educational opportunities, and decreased economic ability. Stigma not only provides real discrimination, but also causes a person or group behave reflecting that stigma, for example,leprosy clients have been labeled as stigma as a disgusting disease and make the client feel that he is disgusting for others(7).Self-efficacy is an individual's perception to take an action he wants. High self-efficacy will encourage the individual to be active and persistent to make an effort. If self efficience is low, then that person will be overwhelmed with doubts about his ability(8). The level of self-efficacy possessed by lepers due to stigma both in the family and community can affect the overall handling of leprosy. If the leprosy patient's self-efficacy is high, leprosy sufferers can seek treatment regularly as a supporter of the healing process and the community does not need to have excessive fear (9).

Based on the background above, this study describes and analyzes the phenomenon of leprosy which has been considered a problem as having a self-efficacy effect on sufferers.

II. Methods

This research was performed in Madura island in March to June 2017 using a qualitative method of phenomenology. Phenomenology studies were used to help researchers explore the level of self-efficacy of lepers who focus on the things that happen to the full awareness of the participants. This research method was chosen as an approach since this study wanted to assess the level of self-efficacy of leprosy sufferers due to the social stigma of leprosy. The problem of lepers undergoing treatment was related to physical, psychological, social and medical needs, disability, and transmission of leprosy in their environment.

Data collection tools in this qualitative study were interviews, voice recorders, stationery, and field notes. Researchers used the principle of immersion, namely positioning themselves as if they are part of the observed phenomenon. When digging research data, the researcher ignored any personal assumptions related to the phenomenon under study, ignored his personal knowledge and understanding, and tried to fully position theirselves as a participant. This study useda purposive sampling technique that has three different inclusion criteria for conducting in-depth interviews and focus group discussions with two different groups.

The number of participants in this study were five people for in-depth interviews, seven people for group discussion forms, and six people who were not affected by leprosy to provide an overview of the phenomenon of stigma against leprosy. Criteria in selecting participants were as follows:

1. Participants in the interview

Participants involved in the interview had the following criteria: registered in the working area of Public Health Center (*Puskesmas*) in Madura island, aged ≥ 18 years, suffering from leprosy for ≥ 1 year, and not experiencing a type 1 reaction or type 2 reaction.

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2. Leprosy participants in group discussion forum activitiesParticipants involved in the discussion forum activities had the following criteria: registered in the working area of Public Health Center in Madura island, had not experienced permanent disability that could interfere with interaction during information retrieval, aged ≥ 18 years, having completed MDT treatment, suffering from leprosy for ≥ 1 year, and not experiencing a type 1 reaction and type 2 reaction.
3. Community participation in group discussion forums

The surrounding community involved in the group discussion forum activities had the following criteria: not a leprosy sufferer, residing in the Madura region, and aged ≥ 18 years.

Data analysis of this study used the Colaizzi method because there was clarification to participants regarding the results of the analysis. The method allowed changes in the results of data analysis based on the classification that had been done to participants. This research has passed the ethical test by the Health Research Ethics Commission of the Faculty of Nursing, Universitas Airlangga. The certificate of this ethical test signed on May 23, 2017 with certificate number 366-KEPK.

III. Results

The overall theme is formed based on participants' answers to questions that refer to the specific objectives of the study. The specific objectives of the study were answered in eight main themes that explained about self-efficacy due to social stigma. Discussion of themes separately in numbering sequence from the first theme to the eighth theme.

Theme 1: Response of Lepers

The response of lepers showed changes in the situation before and after suffering from leprosy. This study found two responses from participants who were first diagnosed with leprosy until after undergoing treatment.Participants showed a negative or a positive response from the current situation and condition. Participants responded to leprosy with a negative response to their condition when they were first diagnosed until they had finished treatment. Participants' negative responses can range from denying problems, bargaining, to depression.

> “*The first time I was surprised, ... number one there was already a factor of abnormalities ... we have collected other things too, lacking of self confidence ... "(P7).*

Participants in this study revealed several considerations through the offers they were currently experiencing. Participants in this study had doubts about their current condition. The participant's statement showing the bargaining response in the participant was expressed by the following participant:

“Yes, hopefully it will not take long, wow, he said, if we have taken routine medicine, we can finish it, hopefully it will be like that" (P12).

Feelings of sadness and disappointment about the problems faced by participants in this study indicated a condition of depression in form of fear, insecurity, and concern about the diagnosis of leprosy they experience.

> *"It's hard ... afraid not get well ..."* (P1).

There was a positive response from the participant related to the participant's acceptance of the reality of his disease. Participants accepted the reality of leprosy that was experienced with the conditions and circumstances.

> *"Difficult ... in my opinion, it is difficult to participate, because the Madurese see from their heredity, it can be contagious and difficult to overcome ... yes we are surrender ..."* (P7).

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"It's all from God ..."(P9).

Theme 2. The Sadness Experience of Lepers

Participants in this study had a sad life experience because of being diagnosed with leprosy. The diagnosis experienced by participants resulted in prolonged sadness due to several aspects, namely loss and difference.

"I cried ... I wanted to run away because I was embarrassed ..."(P1).

"Scared, shy ... yes everything when seen ..."(P5).

"I was clear. (Showing hand) maybe that person saw my hand, it was clear that leprosy was already disgusted, afraid of being infected ..."(P7).

Theme 3. Leprosy Self-Image

Participants have a different view of themselves who have been diagnosed with leprosy. This view becomes a participant's self-image related to the participant's self-concept in viewing himself with good or poor self-awareness based on the signs and symptoms as well as the physical conditions they experience, so that it will have an impact on the participant's psychological condition or self-concept. Participants who expressed themselves with good awareness were participants with a disability level of 0.

"In the past, before taking medicine, my body was stiff ... but now it's normal ..."(P7).

Furthermore, the statements of participants with poor self-awareness related to perceptions of physical and non-physical appearance.

"The point is, what those people are afraid of ... I am a disabled ... people see that my hands are infected of leprosy, obviously disgusted by fear of being infected ..." (P12).

Theme 4. Overview of Disease

Participants in this study had the level of knowledge and information from health workers on the diagnosis of the disease. Participants gave an overview of the disease with a good understanding or a poor understanding of the current condition.

"The treatment takes a long time ... but there are results after being treated ..." (P1).

Most of the participants in this study had no school background. Educational background affects the level of understanding and acceptance of information from participants. Most of the participants considered that the signs of leprosy experienced were symptoms of tinea versicolor.

"Before the red spreads ... it is considered tinea versicolor ..." (P3).

One participant stated that leprosy is a hereditary disease.

"That is a disease ... a hereditary disease ..."(P4).

As many as two participants in the discussion stated that the cause of leprosy was due to food factors.

"Eating cassava tubers, tubers, yams, well ... makes the blood hard. Now this blood can be the same as normal because the person is aware, this is influenced by food factors ... "(P6).

Theme 5. Changes Experienced by Patients

Participants in this study revealed various changes due to leprosy before and after participants were diagnosed with leprosy. These changes in the form of physical changes and activity changes. Participants experienced physical changes before being diagnosed with leprosy by health workers. Physical changes in the form of phlegm, red spots on the skin, and black plaque.

"It was found a little early, if scratched white like tinea versicolor. But if it's not scratched it's not white ... "(P10).

"There are red spots ... "(P7).

"... at that time there were black spots"(P12).

Participants experienced a change in activity after being diagnosed with leprosy. Changes in these activities are withdrawing, less socializing, and decreased activity.

"The influence on daily activities, when you wake up the joints of the body feel stiff ..." (P7).

Theme 6. Efforts To Overcome Problems

Participants had different levels of ability to respond and resolve problems after leprosy has been diagnosed. Participants' efforts consisted of negative efforts and positive efforts and were related to the ability level of the participant.

Participants in this study showed a maladaptive reaction to the community in certain situations and circumstances they experienced after being diagnosed with leprosy by staying away. Then as many as two participants stated their efforts in overcoming the problem after being diagnosed with leprosy, namely trying to cover up their spots when they were in the community.

"Usually,it is covered with clothes ..."(P3).

"In order not to get caught usually using long-sleeved shirts and trousers ..." (P1).

Participants in this study showed an adaptive reaction to the community in certain situations and circumstances after being diagnosed with leprosy by providing support, staying active, seeking treatment, and covering up spots. Participants also had a sense of care not to spread the leprosy transmission and continued to carry out daily activities after being diagnosed with leprosy.

"If I don't have activity, I am unable to eat ... before taking medicine my body was stiff, I held the cigarette butts and suddenly fell, but now it's normal ..." (P7).

"If there are neighbors who look red or white spots, directly I told rhem to visit the health center to report ..."(P12).

Theme 7. Hope of Lepers

Participants diagnosed with leprosy had hope for leprosy not to transmit to others. Leprosy can be treated and does not cause scars. Participants of leprosy hope that the disease was not transmitted to others, could be cured with drugs, and did not imprint on the body.

"Hopefully, it's not contagious to others ... so as not to suffer like this ..."(P12).

"Hopefully, it can be overcome with that drug ..."(P7).

"I want to get well like everyone else and hopefully the spots disappear too ..."(P5).

Theme 8. Stigma of Leprosy

Participants diagnosed with leprosy had their own perceptions of leprosy. Most participants in the group discussion forum stated that leprosy was a frightening disease.

"Leprosy is indeed scary ..."(P9).

"Yeah ... scared ..."(P8, P10, P11).

Participants diagnosed with leprosy felt disgusted with themselves and experienced discrimination from the surrounding community.

> *"People who suffer from leprosy do not want to gather. They feel disgusted ... "*(P7).
>
> *"Most disgusted ..."* (P12).
>
> *"Afraid of being infected ... I don't want to hang out with them ..."*(P8, P9, P10, P11, P12).

IV. Discussion

Perception is a person's internal subjective overview of the external world. Factors that play a role in the formation of perception are cognitive, affective, personality, and culture of someone who comes from the reality of their environment, past experiences, as well as the condition of vomiting from one's emotions and motivations (10). Based on the results of in-depth interviews and group discussion forums, participants said that the response they experienced was divided into two sub-themes, those are negative responses and positive responses. In creating strategies in dealing with loss and grief in this study, leprosy participants carried out in four stages: denying (shock, distrust, shame, and refuse), bargaining, depression (fear, lack of confidence, and worry), and accepting.

Negative responses experienced by participants were associated with physical changes becoming signs and symptoms of leprosy. Participants diagnosed with leprosy showed a negative response starting from the shocking attitude due to the changes in them. Participants did not believe what they were experiencing. As stated by participants in in-depth interviews that they did not ask questions about the signs experienced and felt afraid if affected by leprosy. This incident is called prolonged grieving (chronic sorrow) that occurs as a result of a trigger incident, either internal or external (11). The main concepts of Eakes model theory of chronic sorrow consist of experiences of loss, disparity, chronic sorrow, internal and external management methods, and triggering incidents (12).

Some psychosocial problems due to leprosy felt by lepers and their families are such as feelings of shame and fear. Commonly, the sufferers fear to face the family or community because they do not fairly accept the sufferers. Furthermore, family efforts to hide family members suffering from leprosy because it is considered a disgrace so the family exiling lepers for fear of being infected. Refusal is the participant's initial response when diagnosed with leprosy. Refusal arises because the client does not believe that he is suffering from leprosy. The responses appearing to the client are such as not believing in it and not ready to face the problem. This distrust and refusal arise due to the stressor trigger, which is the diagnosis of leprosy. The stigmatization and strong discrimination in the Madurese community against leprosy has become the people's fear of leprosy. Social stigma against leprosy affects its sufferers to experience various discrimination either from the family or community. This is what makes leprosy a trigger stressor of participants who do not want to be namedlepers.

Participants in this study showed a refusing attitude towards the diagnosis of leprosy experienced to deny the trigger stressors. Illustrated from the participant's statement during the in-depth interview, that the participant knew the disease they were suffering after meeting the health worker but never mentioned the word "leprosy" only referred to as "the disease" which was known as a feared disease by the community.The psychological response of leprosy is anxiety, while leprosy patients try to clarify themselves. The clients make several considerations through the offer they are experiencing at this time and start to express their feelings (13).

Participants in this study revealed several considerations as a bid for their current disease. The uncertainty experienced by participants is related to the desire to cure so as not to have a prolonged effect both physically and socially (9).

Many factors affect the anxiety of lepers, not only in terms of fear of physical disturbances experienced but also fear of being ostracized in the community, feelings of discomfort due to being diagnosed with a negative stigma, and also feelings of fear if the family cannot accept their disease.The experience of stress, anxiety, and depression are signs of a person's deficiencies. Many factors affect the cognitive experience, for example, personality, situation, social, and time (9). The difference in participant responses in this study becomes the difference in the coping mechanism of each individual affected by the trigger.

Chronic sorrow theory states that the trigger is a condition and situation that causes gaps or differences, loss or feeling sad. The stigma and discrimination from the community of where they live became the trigger for the participants in leprosy coping mechanisms. Chronic suffering will not make an individual weaker if it is effective in regulating feelings, both internally and externally. Positive responses expressed by participants indicate the existence of internal coping mechanisms of the participants themselves(14).

Coping is defined as cognitive efforts and actions taken by individuals to overcome problems and demands that are considered detrimental or exceeding the ability of the individual either originating from within themselves or the external environment (15). Someone will achieve success when they are not under stress. Stress gives negative effects on self-efficacy. Self-efficacy from various sources needs to be processed cognitively. Many factors affect the cognitive experience, for example, personality, situation, social, and time (9).

The second type of chronic sorrow is because of an experience of loss in an individual's life. This loss occurs due to a difference between expectations or desires and the reality that occurs (16). Participants in this study felt a difference between themselves and others around them after being diagnosed with leprosy. The difference arises because of the physical changes experienced and innuendo from other people to participants.

Participants consider their condition poorly to be a benchmark for internalized stigma in people with leprosy. Internalized stigma can be characterized as negative feelings about themselves, maladaptive behavior, identity transformation, and negative social perceptions or reactions based on health conditions or illnesses suffered (17). Participants provide an overview of the disease from what they perceive related to the level of knowledge and information possessed by them. The knowledge and information of participants in this study are influenced by information provided by health workers. How participants give an overview of the disease either with a good or a poor understanding is according to their current conditions. So, self-efficacy affects the choice of activities in a particular environment.

Stigma is formed by cognitive and behavioral structures, namely stigma, prejudice, and discrimination(18). Patients who experience stigma have a more severe level of depression compared to patients without stigma. The quality of life of leprosy patients and their families, both socially, economically, and psychologically, is greatly affected by the stigma of the general public(10). Self-stigmatization, in the form of shame because of the deformity of the body and the treatment of others, causes patients to isolate themselves from society. Leprosy patients find it difficult to appreciate or see themselves positively. Some patients find it difficult to accept the fact that they have leprosy, while others may not believe that leprosy patients can recover after treatment. Stigma not only provides real discrimination but also causes a person or group, who experiences a stigma, to behave reflecting that stigma.

Fear of leprosy is sometimes aggravated by methods of handling this disease that is different from other diseases.

The management of separate leprosy patients, either contained in the program or the hospital separation, suggests that leprosy is indeed different and more infectious compared to other diseases. The community then believes this and wants the leprosy patient management away from the community to avoid spreading the disease(19).

V. Conclusion

Psychological, physical, and social changes experienced by participants after being diagnosed, showed the level of self-efficacy of lepers seen from the magnitude dimension that lepers have difficulty adapting after being diagnosed with leprosy.Most people with leprosy show negative responses and describe themselves poorly. Efforts made to overcome the problem of leprosy indicating the level of self-efficacy in the generality dimension has limited scope to be able to take actions that are considered capable of solving problems in the situation. The limitation of leprosy behavior is shown by the majority of participants who have negative efforts in overcoming the problem by closing themselves out of shame, fear, and worry about the community in their environment.Stigma and discrimination of leprosy originating from the lepers, the community, and family are the main sources of triggers in chronic sorrow experienced by lepers so that it affects the level of leprosy self-efficacy.

Correspondence between the context of the situation experienced by lepers and the self-efficacy theory requires follow-up in the form of the application of the theoretical model in real cases.The evaluation is expected to be able to utilize the results of this research as a topic of discussion in class and directly practice in the community, especially in resolving social stigma by developing methods of promoting health in the society.

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