



# Stigma and Self-concept of Leprosy Patients

Anita Lufianti<sup>1</sup>, Srinalesti Mahanani<sup>2\*</sup>, Desi Natalia Trijayanti Idris<sup>2</sup>

<sup>1</sup>Department of Nursing, Universitas An Nuur, Central Java, Indonesia; <sup>2</sup>Department of Nursing, STIKES RS Baptis Kediri, East Java, Indonesia

## Abstract

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**\*Correspondence:** Srinalesti Mahanani, Department of Nursing, Stikes RS Baptis Kediri, East Java, Indonesia. E-mail: nalesti.mahanani@gmail.com  
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**BACKGROUND:** Internalized stigma of leprosy patients suffered because of physical changes or disability suffered. Stigma is the individual's perception of a feeling of a negative attitude and a sense of inferiority felt by the individual who can affect the overall situation.

**AIM:** The purpose of this study was to describe the stigma of leprosy patients at outpatient installation in public hospital of Daha Husada, Kediri.

**METHODS:** The study design used was descriptive. The study population was patients with leprosy at outpatient installation in public hospital of Daha Husada, Kediri, with subject, 50 respondents were selected using purposive sampling technique. The independent variable used in this research was stigma. The instrument used was internalized stigma of mental illness scale. Data analysis using frequency distribution.

**RESULTS:** The research result showed that leprosy patients who experienced medium stigma was 36 respondents (72.0%), and those who experienced moderate stigma were 11 respondents (22.0%). Based on data analysis, the results of the study indicated that stigma had an effect on self-concept ( $p = 0.016$ ).

**CONCLUSION:** The conclusion of this study showed that patients with leprosy got medium stigma primarily on indicators of alienation, stereotypes support, and stigma resistant to the level of disability 2.

## Introduction

The term leprosy comes from Sanskrit, namely, Kushtha means a collection of symptoms of the skin in general. Leprosy is also called Morbus Hansen, according to the name that found Kuman, namely, Dr. Gerhard Armauer Hansen in 1874 so this disease is called Morbus Hansen. Hansen's disease is a chronic infectious disease caused by the bacterium *Mycobacterium leprae*. This disease is a type of granulomatous disease of the peripheral nerves and mucosa of the upper respiratory tract, and lesions on the skin are signs that can be observed from the outside, if left untreated, leprosy can be very progressive, causing damage to the skin, nerves, limbs, and eyes (Andareto *et al.*, 2015) [1]. Disabilities that suffer from natural leprosy patients such as injuries and physical disabilities will have an impact on the psychological condition of the patient. Disability condition causes the emergence of internalized stigma disorder, causing a feeling of inferiority and will feel hopeless because of the physical condition experienced. This embarrassment will cause leprosy patients to withdraw from participating in social activities because leprosy patients feel that their condition is currently bad, such as skin lesions that look terrible and are very dirty (Susanto, 2013) [2]. Based

on the pre-research results, leprosy sufferers feel ashamed if they socialize with the community because of the physical disabilities they experience.

The World Health Organization (WHO) reported in early 2008, the number of leprosy sufferers in the world was 212.802 people. The incidence rate of leprosy in the world according to the WHO in 2011 detected 192,246 people. The Southeast Asia region ranked first out of five regions of 113,759 people. Indonesia as one of the regions in Southeast Asia ranks third in the world after India and Brazil. Java, especially East Java, ranked first and became 30% of the major contributors to leprosy nationally in 2010–2011 in the province of East Java, there were 6326 cases recorded (Dinkes, 2015) [3]. Research according to research by Sari (2018) [4] found that the majority of respondents had a moderate social stigma of 57 people (50%) (Sari, 2018) [4]. The results of the pre-study conducted on December 28, 2018, at the Daha Husada General Hospital outpatient installation in the city of Kediri obtained the number of leprosy patients who visited during the past 3 months on average 143 people. Based on the results of the pre-research data measurements obtained more than 50%, 9 respondents (89%) felt that the patient felt ashamed if socializing with the community because of physical disabilities experienced, patients felt getting negative views from the community about the disease experienced by a

number (88%) a total of eight respondents, while patients consider that the pain experienced is a curse from God as much (88%) that is 10 respondents, from 62% that is 13 respondents feel hopeless about the physical conditions experienced at this time, and respondents feel inferior when sociable in the community as many as 62%, namely, 13 respondents.

Leprosy problems will result in a physical disability that he experienced, namely, defects in the hands, eyes, and feet. This situation will damage the social interaction disorder in sufferers because of the shame and inferiority felt by leprosy patients. It causes the emergence of internalized stigma from individual leprosy patients and will result in an impact of stigma which makes it more difficult to restore life. Stigma causes discrimination, so that it is difficult to get a job, physical disability, society is more crude and less humane and his family become more humiliated and disturbed. Stigma can cause erosion of cell confidence so that patients withdraw and feel self-conscious and ashamed, this is evidenced by the patient always wearing a hat for male patients and hijab for female patients.

Feelings of shame and low self-esteem that is felt by leprosy patients develop very quickly so as to make the psychological condition of a patient suffering from an infectious disease disturbed so that it can worsen the patient's illness. Internalized stigma is a stigma that is shown by a sense of inferiority from sufferers as a result of the final acceptance of their condition. This stigma is characterized by low self-esteem, despair, and guilt or self-blame associated with conditions that are described with negative feelings (Susanto, 2013) [2]. Therefore, to improve the self-esteem of leprosy patients, early detection of the patient's attitude needs to be done so that people with leprosy can increase their self-esteem and positive image. Stigma measurement uses the internalized stigma of mental illness scale (ISMI) developed by the International Federation of Anti-Leprosy Associations (ILEP, 2011) [5]. This study aims to describe the stigma of leprosy patients in Daha Husada General Hospital outpatient installation in Kediri City.

## Methods

The research design used is descriptive. Data were collected at the Daha Husada General Hospital outpatient installation in Kediri City. Data was taken from March 8, 2019 to April 8, 2019. The population in this study was leprosy patients. Respondents were selected based on inclusion criteria including experiencing stigma. Stigma uses ISMI scale structured interview sheets. The subjects of this study were leprosy patients at Daha Husada General Hospital outpatient installation in Kediri City. The sampling technique used was

purposive sampling of 50 respondents. The research variable is the stigma of leprosy patients. Retrieval of data using structured interview sheets. Data analysis is using frequency distribution.

## Results

Frequency distribution of respondents based on stigma in persons affected by leprosy in the outpatient installation of Daha Husada General Hospital, Kediri city on March–April 2019 have shown that the most frequent (36 patients or 72%) is medium heaviness, followed by moderate and mild heaviness (11 patients or 22% and 3 patients or 6%, respectively) (Table 1).

**Table 1: Frequency distribution of respondents based on stigma in persons affected by leprosy in the outpatient installation of Daha Husada General Hospital, Kediri city on March–April 2019 (n = 50)**

Stigma	f	%
Heaviness		
Moderate	11	22.0
Medium	36	72.0
Mild	3	6.0
Total	50	100.0

From the Table 2, it can be seen that the majority of respondents in the categories of self-concept in leprosy patients at Daha Husada Hospital, Kediri City have a low self-concept of 27 people (54.0%) and the rest have high self-concept of 23 people (46.0%).

**Table 2: Categories of self-concept in leprosy patients at Daha Husada Hospital, Kediri City in August 2020 (n = 50)**

Self-concept	f	%
Low	27	54.0
High	23	46.0
Total	50	100.0

Based on the results of the bivariate analysis, the results show that (1) there is a relationship between level of disability and self-concept; (2) there is a relationship between level of disability and stigma; and (3) there is a relationship between stigma and self-concept (Table 3).

**Table 3: Bivariate analysis between stigma and self-concept in leprosy patients at Daha Husada Hospital, Kediri City in August 2020 (n = 50)**

Pearson correlation	Self-concept	Stigma
Disability		
Correlation coefficient	1.000	0.340**
Sig. (two tailed)		0.016
n	50	50
Self-concept		
Correlation coefficient	0.340**	1.000
Sig. (two tailed)	0.016	
n	50	50

## Discussion

Based on the results of research on the stigma of leprosy patients from 50 respondents, it was found that the most experienced medium stigma was

36 respondents (72.0%), and those who experienced moderate stigma were 11 respondents (22.0%).

Stigma in health services can be defined as a social process related to one's experience of an illness (Susanto, 2013) [2]. The social impact of leprosy causes the problem of social isolation and social discrimination in lepers in the community is still difficult, this is because leprosy is an infectious disease, cannot be treated, hereditary disease, curse, and cause disability. Stigma is one of the internal factors that can affect the self-esteem of leprosy patients (Nsagha *et al.*, 2018) [6]. Furthermore, research by Septyana *et al.* (2019) [7] shows that stigma is also felt by families whose children suffer from thalassemia (Septyana *et al.*, 2019) [7]. In his study, Alfian *et al.* (2018) [8] also mentioned that stigma is one of the obstacles for antiretroviral treatment in HIV/AIDS patients, because patients must come to health services which mean that they must recognize that they suffer from HIV/AIDS (Alfian *et al.*, 2019) [8].

Leprosy patients at the Daha Husada General Hospital installation in Kediri City get a pretty heavy stigma in terms of negativity, giving stigma to leprosy patients will go through several stigma formation processes, namely, the process of interpretation, violations of norms that occur in society do not all get stigma from the community, as a deviations of behavior that can cause stigma, the process of defining, leprosy patients who are considered to have deviant behavior after the first stage is done where the interpretation of deviant behavior, discriminatory behavior, the next stage after the second process is carried out, then the community provides discriminatory treatment. The stigma felt by leprosy patients will go through the stages and process of giving stigma until a negative treatment arises in relation to a person's experience in dealing with an illness.

Leprosy patients get an impact from the community, namely, the community has difficulty accepting leprosy patients so that one of the problems for leprosy patients is social isolation. The community will find it difficult to accept leprosy patients because the community assumes that the leprosy will be contagious and the community is afraid if it will experience the same thing and get the impact. The community also assumes that leprosy is a curse disease given by God because of mistakes or violations committed and can cause an impact that is physical disability. Patients will feel ashamed as a result of the culture and perception of the community. This result in leprosy patients will keep the results of the diagnosis of leprosy confidential. This feeling of shame and guilt will result in leprosy patients withdrawing from participation in social activities. This is very clear and can be seen in the answers during the interview that leprosy patients cannot participate in the community because they have leprosy. Leprosy patients who live with family will also

feel afraid because in general they assume that their presence will negatively affect their family life, why is that, because this results in the family being ostracized in a community. Embarrassed and wrong, this leprosy patient experiences psychological effects due to leprosy such as embarrassment, withdrawing by hiding in the house, and some family members and the community considers it uncomfortable for the condition experienced by the patient. Physical disability in leprosy patients results in shame and inferiority as a result of labeling and stigma created by the community around leprosy patients. This will cause uselessness, fear, shame, and low self-esteem of leprosy patients; psychologically, this can be proven by interviews that leprosy patients agree with questions about feeling unable to get along with other people who do not suffer from leprosy, leprosy patients agree about the question of not being able to participate in any community because of leprosy, leprosy patients answered agree to the question about not socializing much with the community because leprosy makes it look strange in the eyes of people, and leprosy patients agree to agree on questions about staying away from the environment so as not to be uncomfortable and inferior, leprosy patients answered agree with questions avoiding people to avoid rejection (Susanto, 2013) [2].

The four indicators used in this structured interview are alienation (68.4%), stereotype support (52.6%), discrimination (52.6%) and stigma resistance (71.1%). Patients who experience sufficient stigma are male, 16 respondents (55.2%), those who experience sufficient stigma are respondents aged 20 -40 years (50.0%), patients who experience sufficient stigma are those in basic education (72, 7%), and those who are self-employed are 11 respondents or (55.0%).

In the indicator of alienation, there were 26 respondents (68.4%) who experienced severe stigma. Alienation or alienation comes from the English words "alienation" and the Latin word "alienato" which means to make something or a state isolated and separate from experience. Alienation describes a situation in which a person feels alienated from himself and turns away from his surroundings so as to encourage that person to be hostile toward others or the community (ILEP, 2011) [5].

Alienation in leprosy patients is a condition that makes leprosy patients become isolated and abandoned, leprosy patients are ignored through less attention from the public. Leprosy patients who are not considered to make self-esteem down and reduced so that leprosy patients turn away from the environment and away from society. It provides data that leprosy patients are aware of the feeling of being alienated from the environment because of leprosy, suffering from leprosy makes life worse, people who do not suffer from leprosy will not understand what they feel, leprosy patients are ashamed and humiliated because of leprosy, leprosy sufferers are



disappointed because of leprosy, leprosy sufferers feel inferior to other people who do not suffer from leprosy. The impact occurs in leprosy patients who experience severe stigma in isolation indicators, namely, leprosy patients can lead to problems of social isolation and social discrimination in lepers in the community. Acceptance of leprosy in the community is still difficult, this is because leprosy is a contagious disease, cannot be treated, hereditary disease, curses, and causes of disability.

In the stereotypical support indicator, there are 20 respondents (52.6%) of respondents who experienced enough stigma. Stereotypes are beliefs about certain characteristics of certain group members (Susanto, 2013) [2]. Stereotypes are expressions of guilt, fear, and punishment of guilt (Rahman, 2013) [9].

The perception of leprosy patients has certain characteristics which are the beliefs or thinking ability of leprosy patients while the community perceives that suffering from leprosy is a result of wrong actions and violates a rule or prohibition so that they are then punished by God for their own mistakes. This is evidenced by leprosy patients agreeing with the questions of the pair/leprosy changing leprosy treatment of leprosy patients, leprosy patients agreeing to the questions of the public can know that leprosy patients suffer from leprosy from appearance or disease that appears in the body, leprosy patients answer agree with the question because of leprosy, the leprosy patient needs someone else to make a decision, and the patient answers in agreement with the question that leprosy patients cannot participate in anything with the community because of leprosy. The impact of stigma enough on indicators of stereotypical support is that stigma will result in a social discrimination that causes an impact of fear on leprosy patients and families to seek help for what they need.

In the discrimination indicator, there were 20 (52.2%) respondents who experienced stigma. Discrimination is a behavioral component which is a negative behavior toward an individual because the individual is a member of a particular group (Taylor *et al.*, 2009) [10]. Stigma and discrimination are interconnected in the psychological life of leprosy patients. Stigma reflects an attitude and discrimination is an action and behavior. This shame causes leprosy patients to withdraw from the environment (Susanto, 2013) [2].

Public acceptance of leprosy depends on community perceptions in the environment surrounding leprosy patients. Discrimination and negative reactions from family, friends, and the community make leprosy patients experience psychological disorders and withdraw from the environment. Withdrawal itself has a meaning that is an action that will be taken when they physically or psychologically choose regardless of or limit their interaction with the surrounding community. Public acceptance of leprosy depends on the perception of the community in the environment around leprosy

sufferers. Discrimination and negative reactions from family, friends and society make people with leprosy experience psychological disorders and withdraw from the environment. Withdrawal has the meaning of an action that will be taken when they choose physically or psychologically without regard to or limiting their interaction with the surrounding community. Withdrawal is evidenced by the patient answering agree to the questions (1) the community isolates themselves because of leprosy, (2) the community considers the leprosy patient does not succeed in living because he suffers from leprosy, (3) the leprosy patient refuses and is not considered in the community because he suffers from leprosy, (4) people often feel sorry or ashamed like small children because of leprosy, (5) no one is interested in approaching because of leprosy, (6) leprosy sufferers do not socialize much because leprosy will make other people look strange, (7) prejudice / negative judgment about leprosy making isolation from the environment, (8) away from the environment so as not to embarrass friends and family, (9) gathering with people with leprosy makes them uncomfortable and unable to get along, (10) people with leprosy avoid society to avoid rejection.

The impact for patients with severe stigma on indicators of discrimination is that leprosy sufferers experience a grieving reaction where leprosy sufferers must accept the reality of life from the environment, experience pain due to loss, adjust to the environment, and emotionally empower back into new relationships.

In the stigma resistance indicator, there are 27 respondents (71.1%) who experience minimal stigma. Resistant stigma is the development of beliefs that oppose stigma can help individuals with the hope that they can find a satisfying life and in their recovery from mental illness (ILEP, 2011) [5].

There are also leprosy patients who do not respond to stigma, they assume that an illness if it has been treated and treated will heal and leprosy patients believe that they will live like other people, this is evidenced by interviews conducted that leprosy patients agree with the question basically can undergo live as normal as desired, leprosy patients have a pleasant life despite suffering from leprosy. The impact for patients who experience minimal stigma on stigma resistant indicators is that patients have begun to accept the reality of life that occurs, leprosy patients have made plans to overcome the problem. This patient's condition begins to calm down in the face of problems that are being faced that are related to the state of the disease that starts leading to social problems in the community.

The results show that most of the respondents who experience enough stigma are respondents with low education as many as 8 respondents (72.7%).

Leprosy patients in the outpatient installation of Daha Husada General Hospital in Kediri City have a low level of education. This is not in line with research

Permatasari and Arianti [11], because the higher the level of education, the higher the pattern of knowledge and understand how to deal with a problem because in general people with higher education will have more extensive knowledge. Leprosy patients who have low education will have less experience and less extensive insight so that the situation raises the lack of knowledge (Permatasari and Arianti, 2016) [11].

The results of the study showed that the majority of respondents experienced sufficient stigma, namely, respondents aged 40–60 years, 8 respondents (61.5%) and those who experienced severe stigma were 4 respondents (57.1%). Leprosy patients in the outpatient installation of Daha Husada General Hospital, Kediri City, aged 40–60 years, have low knowledge. This affects the stigma or poor behavior of leprosy patients.

Based on the results of research, the data found that the majority of respondents experienced enough stigma, that is, most of the civil servants experienced severe stigma that is, as much as 3 respondents or 75.0%. The results of this study are inversely proportional to the study Soedarjatmi, most of the patients do not work, besides it is difficult to find work leprosy patients feel afraid if the leader and his friends know that the respondent has leprosy and the respondents are very aware of fatigue will result in recurrence of the disease, with not working respondents stated that they did not have income (Dkk, 2009) [12].

Leprosy has a wide influence on the lives of sufferers, ranging from marriage, work, personal relationships, and business activities to their presence at events in the community. Most respondents have suffered from leprosy between 1 year and 5 years, within a period of time, the respondent must always seek medical treatment and take medication regularly, if until late in treatment, the respondent stated that the disease would reappear. Stigma causes discrimination so that it is difficult to get accommodation and employment because of the clinical manifestations that arise and the complications that occur. The community feels reluctant to live side by side with leprosy patients.

Most leprosy patients are civil servants because civil servants can elevate a person's social status to the highest level, giving more respect from the community, so if leprosy patients get stigma, the social status will decrease.

One effect arising from the existence of stigma is the occurrence of physical disability. Based on the results of the study it was found that level 2 disability was experienced by 23 respondents (60.5%). Stigmatization due to physical disability is part of a group with physical deformities so that there are deformities that are seen in leprosy patients.

The level of disability of leprosy patients in Daha Husada General Hospital outpatient installation in Kediri City is an impact that occurs because leprosy

patients are shy and discouraged so that leprosy patients are not determined to seek treatment and do not perform routine hospital care, this is in line with the results of observations made by researchers that the level of disability of leprosy patients reaches the level of disability 2 which is marked by the presence of disabilities that appear in leprosy patients including disability in the eyes, hands, and feet.

### **Self-concept in leprosy patients**

Based on the research results, it was found that the low self-concept was 27 people (54%). According to Yusuf, a positive self-concept gives a person a sense of meaning, holiness, and consistency (Yusuf, 2015) [13]. A healthy self-concept has a high degree of stability and results in positive feelings about oneself. The components of self-concept that is often considered by nurses are identity, body image, and role appearance. The range of self-concept responses according to Stuart and Sudden in Suhron [14] is (1) self-actualization, namely, self-questions about positive self-concepts with a background of experience that is real success and acceptance. (2) Positive self-concept, when individuals have positive experiences in self-actualization. (3) Low self-esteem is a transition between an adaptive self-concept response and a maladaptive self-concept response. (4) Identity disorder is the failure of individuals to integrate aspects of childhood identity into the maturity of the psychosocial aspects of personality in harmonious adulthood (Suhron, 2017) [14].

According to Tarwoto [15], self-concept is influenced by several factors as follows: (1) Level of development and maturity. (2) Culture. (3) External and internal sources, strength and development in individuals greatly influence self-concept. In internal sources, such as humorous people, individual coping is more effective. The large external factor can be obtained from the community and economic factors. (4) The experience of success and failure, there is a tendency that a history of success will improve self-concept and vice versa. (5) Stressors in life, such as marriage, new job, tests, and fear. If the individual's coping is inadequate, it will lead to depression, withdrawal, and anxiety. (6) Age, illness, and trauma, old age, and illness will affect their self-perception (Tarwoto, 2010) [15].

Individuals from birth and begin to grow know themselves first by getting to know other people. When we were little, the important people around us were parents and siblings. How other people know us to form our self-concept, self-concept can be formed due to various factors, both external and internal. The factors become even more specific and will be closely related to the self-concept that will be developed by the individual (Sari, 2017) [4].

## Conclusion

Leprosy patients get sufficient stigma, especially on indicators of alienation, stereotypical support, discrimination, and stigma resistance with a level of disability 2 in the outpatient installation of Daha Husada General Hospital, Kediri City.

From the results of the study, it was found that leprosy patients get enough stigma leprosy patients are expected to increase and grow confidence by reducing the level of disability using the principle of 3M that is examining the eyes, hands, and feet of physical trauma, caring for themselves, and accepting the state of self.

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### **Data availability statement**

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

### **Ethical consideration**

Ethical clearance taken from the Health Research Ethics Commission (KEPK) Stikes Kediri Baptist Hospital. This research has passed ethics with letter number 077/28/III/EC/KEPK-3/STIKES RSBK/2020.

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