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## CORRELATION PERCEIVED STIGMA AND QUALITY OF LIFE OF LEPROSY PATIENTS

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### Abstract

**Background:** One problem that hinders leprosy prevention efforts is the existence of stigma. Perceived stigma refers to the perceptions and subjective awareness of lepers of what the community thinks or do to themselves which can reduce quality of life (QOL).

**Objective:** To analyse the correlation perceived stigma and QOL of leprosy patients.

**Research Methods:** This study involved 30 leprosy patients. Baseline data were collected on the research sample, assessment of perceived stigma using EMIC questionnaire and QOL assessment using WHOQOL-BREF questionnaire. The collected data is then processed and statistically analyzed used the Pearson correlation test.

**Results:** This study found a significant correlation perceived stigma and QOL ( $p=0,011$ ;  $r= -0,459$ ). The demographic characteristics were highest in the age range of 18-39 years, male sex, high school education, income below the city minimum wage and married status. Most of them had perceived negative stigma. Covering illness from others and discussing their illness closest people are the dominant factor affecting perceived stigma. They had ordinary QOL subjectively, not satisfied to health condition, physical domain was the most affected by leprosy and had a good QOL.

**Conclusion:** There is a significant correlation perceived stigma with QOL.

### Introduction

#### Background

Leprosy is one of the neglected tropical diseases (NTDs) and causes medical, social, economic, cultural, security and national resilience problems.<sup>1,2</sup> Leprosy develops slowly and can cause dysfunction and serious nerve damage which can lead to disability and ultimately lead to stigma and discrimination.<sup>3,4,5</sup> Stigma is a negative view and discriminatory treatment of leprosy patients so that it hinders efforts for leprosy patients and their families to lead a normal social life like other people.<sup>5</sup> There are three forms of stigma in leprosy patients, namely enacted stigma, perceived stigma and internalized (self) stigma.<sup>2,3,6</sup> Enacted stigma refers to the act of being open to medical discrimination and directly insulting leprosy patients. Perceived stigma refers to the perceptions, hopes, fears, and subjective awareness of leprosy patients about what the community thinks or will do about them.<sup>2</sup> The consequence of being enacted and perceived stigma is that the leprosy patient believes what other people think and say about him, causing a sense of insecurity and decreased self-esteem which can develop into internalized (self) stigma.<sup>2,7</sup> Internalized stigma, describes the process carried out by an individual to accept criticism from society and incorporate it into the personal values and sense of self of the individual and cause leprosy patients to move away from the community.<sup>2,6-8</sup> Perceived stigma can be assessed using the Explanatory Model Interview Catalogue (EMIC) questionnaire.<sup>9,10</sup>

Leprosy patients often experience difficulties in physical, psychological, environmental and social interactions, which can reduce their quality of life. Quality of life is an individual's perception of his position in life, in the context of culture, the value system in which they are and their relationship to life goals, expectations, standards, and other related.<sup>11,12-14</sup> The instrument used to measure the quality of human life broadly from physical, psychological, environmental and social aspects is the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire.<sup>13,15,16</sup>

Research on the correlation perceived stigma and quality of life of leprosy patients is still small. By knowing the relationship between perceived stigma and quality of life, it is hoped that ways to prevent and overcome perceived stigma can be found so that the quality of life of leprosy patients can improve.



## Method

### Research sample

The study sample was taken from 30 leprosy patients who came to Sumatera University Hospital, dr. Pirngadi Hospital, and four community health centers in Medan using consecutive sampling techniques.

### Study design

This research is an observational analytic study with cross sectional method. Baseline data were collected on the research sample, assessment of perceived stigma using the Explanatory Model Interview Catalog (EMIC) questionnaire and quality of life assessment using the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire

### Statistic analysis

Data from the study were statistically analyzed using the SPSS computer program version 22.0. Pearson correlation test is used to analyse the correlation of perceived stigma and the quality of life of leprosy patients.

## Results

In this study, the demographic characteristics of leprosy patients in this study were highest in the age range of 18-39 years (66,7 %), male sex (70%), high school education level (70%), income below the city minimum wage of Medan (56,7%) and married status (56,7%). For complete data on the characteristics of the subjects of this study are presented in table 1 below.

*Table 1. Overview of Characteristics of Research Subjects*

Characteristics of Research Subjects	n	%
Age (years)		
• 18 – 39 years	20	66,7
• 40 – 61 years	7	23,3
• 62 – 83 years	3	10,0
Gender		
• Male	21	70,0
• Female	9	30,0
Education		
• Uneducated	0	0
• Elementary School	1	3,3
• Junior High School	4	13,3
• Senior High School	21	70
• College	4	13,3
Income		
• Below the minimum wage for the city of Medan	17	56,7
• In accordance with the minimum wage for the city of Medan	5	16,7
• Above the minimum wage for the city of Medan	8	26,7
Marital Status		
• Single	11	36,7
• Married	17	56,7
• Widower/Widow	2	6,7



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Characteristics of the perceived stigma of leprosy patients according to the EMIC questionnaire are the assessment of negative or positive perceived stigma based on the total EMIC score and the perceived stigma profile.

According to the total score of the EMIC questionnaire, most of the research subjects in this study had negative perceived stigma (56,7%). Median score of total perceived stigma is used as a cut off point.<sup>2,17</sup> This can be seen in table 2.

**Table 2. Perceived stigma of research subject according to the total score of the EMIC questionnaire**

Variable	Mean (Standard deviation)	Median	n	%
Total EMIC score	13,63 ± 7,41	14		
Positive Perceived stigma (<14)			13	43,3
Negative Perceived stigma negatif (≥14)			17	56,7
Total			30	100,0

Perceived stigma profile is obtained from the most “yes” answers. From the perceived stigma profile, it can be seen what dominant factor affecting the perceived stigma of leprosy patients.<sup>17</sup> The dominant factors are factor covering their illness from others (90%) and discussing their illness with those closest to them (90%). This can be seen in table 3 below.

**Table 3. Perceived stigma profile of research subject answering “yes” (n=30)**

EMIC question	Answering “yes”	
	n	%
Keep others from knowing if possible	27	90,0
Disclosed to the close person about this condition	27	90,0
Think less of yourself because of this problem	1	3,3
Shame or embarrassment due to leprosy	5	16,7
Less respect from others because of this	2	6,7
Contact with you would have bad effects on others	6	20,0
Others have avoided you because of this problem	3	10,0
Others might refuse to visit your home	3	10,0
Others would think less of your family	7	23,3
Social problems to your children in community	5	16,7
Disease causes problems for your marriage	4	13,3
Causes marriage problems to your family	1	3,3
Asked to stay away from work or social group?	1	3,3
Decided on self to stay away from social group	9	30,0
Others presume you have other health problems	7	23,3



Characteristics of the quality of life of leprosy patients according to the WHOQOL-BREF questionnaire in this study are the subjective assessment of quality of life, satisfaction of health condition, the domain of quality of life and quality of life based on the total score of WHOQOL-BREF questionnaire.

A subjective assessment of quality of life is obtained from answers to the first question of WHOQOL-BREF questionnaire. The majority of this research subjects have ordinary subjective assessment of quality of life (60%). This can be seen in table 4 below.

*Table 4. Subjective assessment of quality of life*

Quality of life	n	%
Very bad	0	0
Bad	3	10
Ordinary	18	60
Good	9	30
Very good	0	0
Total	30	100,0

Satisfaction of health condition is obtained from answers to the second question of WHOQOL-BREF questionnaire. The majority of this research subjects have not satisfactory satisfaction of health condition (36,7%). This can be seen in table 5 below.

*Table 5. Satisfaction of health condition*

Satisfaction level	n	%
Very unsatisfactory	1	3,3
Not Satisfactory	11	36,7
Ordinary	10	33,3
Satisfying	8	26,7
Very satisfy	0	0
Total	30	100,0

Assessment of the quality of life domain aims to determine the domain that provides the greatest contribution in supporting one's quality of life. The smallest domain of quality of life for leprosy patients based on the WHOQOL-BREF questionnaire is the physical domain (mean score 51 with a standard deviation of 12,97) and the largest is the social relationship domain (mean score 66,01 with a standard deviation of 13, 87). This means that the domain of quality of life most affected by leprosy in this study is the physical domain (table 6).

*Table 6. Domain of quality of life*

Quality of life	n	Min-Max	Mean	Median	SD	95% CI Mean
Physical	30	10-69	51	53	12,97	46,15- 55,84
Psychological	30	25-69	56,95	56	11,22	48,57- 56,95
Social relations	30	31-81	66,01	62,5	13,87	55,65- 66,01
Environment	30	31-94	63,1	63	11,43	58,82- 67,37
Total	30	42-82	64,83	66	11,72	60,45- 69,21

The quality of life based on the total score of the WHOQOL-BREF questionnaire is classified as poor quality of life if the average quality of life score is <50 and the quality of life is good if the average quality of life score is  $\geq 50$ .<sup>18</sup> The majority of this research subjects have a good quality of life (table 7).



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*Table 7. The quality of life based on the total score of the WHOQOL-BREF questionnaire*

Quality of life	n	%
Poor (<50)	2	6,7
Good (≥50)	28	93,3
Total	30	100,0

In this study, after the data was collected, the Shapiro-Wilk normality test was carried out which showed the EMIC score to measure the perceived stigma and the WHOQOL-BREF score to assess the quality of life of leprosy patients with normal distribution, so the Pearson correlation test was used. Based on the statistical analysis of the Pearson correlation test of 30 research subjects, it was found that there was a significant relationship between perceived stigma and quality of life with a p value of 0.011 and a correlation r value of -0.459 indicating a negative correlation with moderate correlation strength (table 8).

*Table 8. Correlation Perceived Stigma and Quality of Life of Leprosy Patients*

	Quality of life
<i>Perceived stigma</i>	r = - 0,459 p = 0,011 n = 30

### Discussion

In this study, it can be concluded that the largest age range is in the 18-39 year group as many as 20 subjects (66,7%). The results of this study are relevant to previous research by Rahayuningsih, who reported that leprosy was mostly in the 18-40 years age range, namely 34 people (72.34%).<sup>18</sup> Leprosy can occur at all ages, namely infants to old age and most often occurs around the age of 20 to 30 years, namely at a young and productive age because they have a greater risk of being exposed to the source of leprosy transmission.<sup>1,19-21</sup>

The majority of the subjects of this study were male as many as 21 people (70%). This result is relevant to the research conducted by Pane, et al. , which reported more male research subjects than female subjects, namely male as many as 14 people (82.4%).<sup>20</sup> The results of several studies in the world except in several countries in Africa regarding leprosy found that leprosy patients are more male than female.<sup>1</sup> This can be caused by social, cultural, and community education factors. In certain cultures women's access to health services is very limited. The incidence of leprosy is more common in males and is also associated with greater male mobility so that the opportunity to contact leprosy patients is greater and men are also more active in seeking treatment.<sup>1,19-21</sup>

In this study, the most research subjects were with high school education, namely 21 people (70%). This is in accordance with research conducted by Menaldi, who reported that the most research subjects were with secondary school education, namely 23 people (57.5%).<sup>22</sup> The theory of behavior formation according to Notoadmodjo states that education level is one of the elements that determines a person's experience and knowledge, both in science and in social life. People with higher education tend to behave positively.<sup>23</sup> High school education level is the level of secondary education in the education system in Indonesia. With this fairly good education, research subjects behave positively when they find out that they have leprosy symptoms and try to seek treatment.

In this study, the most research subjects with income below the minimum wage in Medan as many as 17 people (56.7%). This result is consistent with research conducted by Rahayuningsih, which reported the most research subjects with income below the minimum wage in Tangerang as many as 43 people (91.49%).<sup>18</sup> Income has a relationship with the incidence of leprosy. Leprosy patients with low income are unable to meet good nutritional needs for themselves and their families. This causes a decrease in immunity against infectious diseases including leprosy. Low income is also associated with the inability to have adequate housing. Occupancy that is denser and slum means the possibility of contact with infectious diseases is getting bigger.<sup>24</sup>

In this study, the most research subjects were married as many as 17 people (56.7%). This is in accordance with the research conducted by Ibikunle, et al., who reported most of the research subjects were married, as many as 49 people (77.8%).<sup>25</sup> Leprosy can cause social complications in marital relationships. A study in South Africa



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reported that one-third of leprosy patients have been abandoned by their partners, especially female leprosy patients. However, in their culture, especially in rural areas, women are usually more obedient and prefer to maintain a marriage.<sup>26</sup> The majority of research subjects are male and may have leprosy after marriage so that they do not experience difficulties in finding a life partner. The wife of the research subject may obey religious and cultural values to maintain her marriage.

In this study it can be concluded that most of the research subjects had a negative perceived stigma as many as 17 people (56.7%). The corresponding results were also obtained in a study conducted by Astutik, et al., as many as 153 people (50.4%) were found with a negative perceived stigma.<sup>2</sup> Negative perceived stigma indicates that leprosy patients experience a strong stigma that comes from themselves.<sup>2,9,10</sup> This condition must be overcome because it can fall into a condition of internalized (self) stigma. In internalized (self) stigma, isolation of the surrounding environment occurs.<sup>27</sup>

The perceived stigma profile of research subjects is obtained from the answer "yes" when answering the EMIC questionnaire and this shows the dominant factor influencing the perceived stigma experienced by research subjects in this study according to the EMIC questionnaire. The dominant factor affecting the perceived stigma experienced by research subjects in this study according to the EMIC questionnaire was covering the disease from others and discussing the disease with the closest people as many as 27 people (90%). The results of this study are consistent with the research conducted by Adhikari, et al., the research subjects mainly answered "yes" to the question about covering up their disease from others as many as 89 people (65.9%), had less self-respect as many as 78 people (57.8%) and told their closest people about the leprosy they suffered as many as 55 people (40.7%).<sup>17</sup> Each question contained in the EMIC questionnaire represents a different aspect of perceived stigma so that it can assess the profile of perceived stigma. By knowing the profile of perceived stigma, it can be seen that the dominant factor influencing the perceived stigma experienced by leprosy patients so that the perceived stigma can be handled properly.<sup>17,28</sup>

In this study, the subjective assessment of research subjects on quality of life was at most ordinary as many as 18 people (60%). This is different from the results of research conducted by Ulfa, who reported that the subjective assessment of research subjects on the quality of life was mostly good, namely 15 people (75%) in areas with self-care groups and 17 people (85 %) in an area without a self-care group.<sup>29</sup> The WHOQOL-BREF questionnaire consisted of 26 questions and consisted of 2 parts, namely the overall quality of life and the quality of health in general.<sup>18</sup> The overall quality of life was assessed subjectively. Some research subjects tended to feel shy and hesitated in answering questions about their overall quality of life, which could cause differences in their answers.<sup>29</sup> The majority of the subjects of this study rated their quality of life as ordinary because it was strongly influenced by subjective assessments. The level of ordinary quality of life is at a lower level than the good quality of life. This shows that the patient subjectively has decreased quality of life.

In this study, the assessment of leprosy patient satisfaction with their health conditions was at most not satisfactory as many as 11 people (36.7%). This is different from the research conducted by Ulfa, where the most of the research subjects were satisfied with their health conditions, namely 9 people (45%) in areas with self-care group and as many as 11 people (55%) in areas without self-care group.<sup>29</sup> Oksuz and Malhan state that quality of life is a multidimensional construct that can be measured in various approaches including a complete feeling of one's well-being and includes overall aspects of happiness and life satisfaction.<sup>18,30</sup> Satisfaction with health conditions is assessed subjectively. Subjects in this study experienced decreased quality of life subjectively, so it is relevant if they also experience decreased satisfaction with their health conditions.

The domain of quality of life most affected by leprosy in this study is the physical domain (mean score 51 with a standard deviation of 12.97). This is in line with research conducted by Ulfa, who reported in areas with self-care group, the domain of quality of life that is most affected by leprosy is the physical domain (mean score 65.18 with a standard deviation of 6,01). Whereas in areas without self-care group, the domain of quality of life that is most affected by leprosy is the environmental domain (mean score 49.38 with a standard deviation of 14.39).<sup>29</sup> The largest mean value from each domain indicates the quality of life domain that is the best or the least affected in the quality of life of the leprosy patient, whereas the smallest mean value indicates the quality of life domain that is the worst or the most affected in quality. the life of the leprosy patient. A large standard deviation value indicates that there are more variations in the answers in the quality of life domain, on the other hand, a smaller value indicates less variation in answers.<sup>18,29</sup> The physical domain is the quality of life domain associated with pain that interferes with activities, dependence on medical care, the ability to socialize, sleep satisfaction, daily





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life activities and work capacity.<sup>16,18,29</sup> Leprosy rehabilitation consists of medical and socio-economic fields. Medical rehabilitation consists of physical and mental treatment and rehabilitation. Treatment includes the Prevention of Disability and self-care group. The self-care group provides opportunities for leprosy patients to be able to actively carry out self-care so that they can improve their health status, reduce the number of disabilities, reduce leprophobia and can increase the self-confidence of leprosy patients.<sup>29</sup>

In this study, the most research subjects with good quality of life as many as 28 people (93.3%). This is different from the results of research conducted by Rahayuningsih, who reported 27 people (57.45%) with poor quality of life and 20 people (42.55%) with good quality of life.<sup>18</sup> The WHOQOL-BREF questionnaire not only provides a score in each domain of quality of life, but also provides a total score of quality of life. Each question uses 5 response scales, the higher the total score indicates the better the quality of life level.<sup>18,29</sup> In this study, the most research subjects with good quality of life were 93.3%. However, it should be noted, there are 6.7% of research subjects who still have a poor quality of life. The quality of life of the study subjects in terms of the total score of the WHOQOL-BREF questionnaire is the majority of good. This can show the success of the leprosy management program in Medan. However, there are still research subjects with low quality of life which is a problem for the leprosy management program in Medan. Research subjects with poor quality of life are likely to be the most affected in the physical domain of quality of life. Leprosy rehabilitation through the self-care group program is expected to improve the quality of life of this research subject in particular and leprosy patients in general.

Based on the statistical analysis of the Pearson correlation test of 30 research subjects, it was found that there was a significant relationship between perceived stigma and quality of life with a p value of 0.011 and a correlation r value of -0.459 indicating a negative correlation with moderate correlation strength. Slamet, et al. also get the appropriate results, namely there is a significant relationship between perceived stigma and the quality of life of leprosy patients with a p value <0.000 and a correlation r value of -0.389 which shows a negative correlation with low correlation strength, but in this study the perceived stigma factor is said to have a strong correlation at most.<sup>31</sup> Perceived stigma is a stigma seen from the perspective of leprosy patients. It is the devaluation, shame, secrecy, and withdrawal that is triggered by applying negative stereotypes to oneself. This can develop from discrimination from family members, friends or the community.<sup>2,7</sup> The quality of life of leprosy patients and their families, both in terms of social, economic and psychological aspects, is strongly affected by the existence of stigma by the general public.<sup>12,32</sup> In this study, there was a significant and statistically significant relationship between perceived stigma and quality of life of leprosy patients. The greater the perceived stigma, the lower the quality of life of leprosy patients and vice versa. Although it has a significant relationship, perceived stigma is not the only factor that has a relationship with the quality of life of leprosy patients, but the strength of the correlation is quite good, that is, it has a moderate correlation. Thus, the perceived stigma is statistically proven to have a contribution to the quality of life of leprosy patients in Medan.

### Conclusion

There is a significant correlation between perceived stigma with quality of life with the direction of negative correlation with moderate correlation strength.

### Suggestion

The assessment of perceived stigma using the EMIC questionnaire and the quality of life using the WHOQOL-BREF questionnaire can be used as a routine procedure in examining leprosy patients.

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