Correlation between perceived stigma and quality of life of Leprosy patients

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ABSTRACT

Background: Stigma is one of many problems that hinders leprosy prevention efforts. Perceived stigma refers to the perceptions and subjective awareness of leprosy patients what the community thinks or do to themselves which can reduce quality of life (QOL). This study aimed to analyze the correlation between perceived stigma and QOL of leprosy patients

Methods: This study involved 30 leprosy patients and the baseline data were collected through interview. We assessed perceived stigma and QOL respectively by using Explanatory Model Interview Catalogue (EMIC) and World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire. Pearson correlation test is used to analyze the collected data.

Results: There was a significant correlation between perceived stigma and QOL (p=0.011, r= -0.459). The majority of research subjects were aged between 19-40 years old with male sex predominance, senior high school education, income below the city minimum wage and married status. Most of them had negative perceived stigma. Covering illness from others and discussing their illness closest people were the dominant factors 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 was a significant correlation between perceived stigma and QOL.

Keywords: Leprosy, perceived stigma, quality of life

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INTRODUCTION

Leprosy is one of the neglected tropical diseases (NTDs) and causes medical, social, economic, cultural, security and national problems.1,2 Leprosy develops slowly and can cause dysfunction and severe nerve damage, leading to disability and ultimately leading to stigma and discrimination.3-5 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.5 There are three forms of stigma in leprosy patients, namely enacted stigma, perceived stigma and internalized (self) stigma.2,3,6 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.3 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.2,7 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.2,6-8 All of the aspect of these perceived stigma have been well documented and can be inferred from the Explanatory Model Interview Catalogue (EMIC) questionnaire.9,10

Leprosy patients often experience difficulties in physical, psychological, environmental and social interactions, reducing 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.11,12-14 WHO defines the measure of the quality of human life which include physical, psychological, environmental and social aspects as mentioned in the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire.13,15,16

There is only a handful of research about the correlation of perceived stigma and quality of life of leprosy patients. Knowing the relationship between perceived stigma and quality of life might provide hope for a solution to prevent and overcome perceived stigma.

METHODS

This research was an observational analytic study with the cross sectional method. This
study was conducted after approval from the Ethics Commission in the Faculty of Medicine of Universitas Sumatera Utara/H. Adam Malik General Hospital number 112/TGL/KEPK FK USU-RSUP HAM/2020. The study 30 Leprosy patients taken consecutively from leprosy patients who came to Universitas Sumatera Utara Hospital, dr. Pirngadi Hospital, and four community health centers in Medan.

Baseline data were collected on the research sample. The assessment of perceived stigma was done using the Explanatory Model Interview Catalog (EMIC) questionnaire. Quality of life assessment was done using the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire. Data from the study were statistically analyzed with statistical software. Pearson correlation test was used to analyze the correlation of perceived stigma and leprosy patients’ quality of life.

**RESULTS**

In this study, the demographic characteristics of leprosy patients in this study were highest in the age range of 19-40 years (66.7%), male sex (70%), senior high school level of education (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.

According to the EMIC questionnaire, characteristics of leprosy patients’ perceived stigma were the assessment of negative or positive perceived stigma based on the total EMIC score and the perceived stigma profile. Based on the EMIC questionnaire’s total score, most of the research subjects in this study had a negative perceived stigma (56.7%). The median score of total perceived stigma was used as a cut off point. This can be seen in table 2.

Perceived stigma profile was obtained from the most “yes” answers. The perceived stigma profile could be seen as the dominant factor affecting leprosy patients’ perceived stigma. The dominant factors were factors covering their illness from others (90%) and discussing their illness with those closest to them (90%). These can be seen in Table 3 below.

Characteristics of the quality of life of leprosy patients according to the WHOQOL-BREF questionnaire in this study were the subjective assessment of the 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 the quality of life was obtained from answers to the first question of the WHOQOL-BREF questionnaire. The majority of these research subjects had an ordinary subjective assessment of the quality of life (60%). This can be seen in table 4.

The satisfaction of the health condition was obtained from answers to the second question of the WHOQOL-BREF questionnaire. The majority of these research subjects had not satisfactory satisfaction with their health condition (36.7 %). This can be seen in table 5.

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 was the physical domain (score 51±12.97), and the largest was the social relationship domain (score 66.01±13.87). This means that the domain of quality of life most affected by Leprosy in this study was the physical domain (table 6).

The quality of life based on the total score of the WHOQOL-BREF questionnaire was 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 ≥50. The majority of this research subjects had a good quality of life (table 7).

### Table 1. Overview of Characteristics of Research Subjects

| Characteristics of Research Subjects | Frequency (n=30) | n   | %  |
|--------------------------------------|-----------------|-----|----|
| **Age**                              |                 |     |    |
| 19 – 40 years old                    |                 | 20  | 66.7|
| 41 – 62 years old                    |                 | 8   | 26.7|
| 63 – 84 years old                    |                 | 2   | 6.7 |
| **Gender**                           |                 |     |    |
| Male                                 |                 | 21  | 70  |
| Female                               |                 | 9   | 30  |
| **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               |                 | 17  | 56.7|
| Within minimum wage                  |                 | 5   | 16.7|
| Above the minimum wage               |                 | 8   | 26.7|
| **Marital Status**                   |                 |     |    |
| Single                               |                 | 11  | 36.7|
| Married                              |                 | 17  | 56.7|
| Widower/Widow                        |                 | 2   | 6.7 |

*According to the minimum wage of the city of Medan*
### 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     | 30 | 100.0 |
| Positive Perceived stigma (<14) | 13                        | 43.3   |    | 43.3 |
| Negative Perceived stigma (≥14) | 17                        | 56.7   |    | 56.7 |

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

| EMIC question                                      | Answering “yes” |
|---------------------------------------------------|------------------|
| • 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 the community| 5 16.7           |
| • The 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 the social group| 9 30.0          |
| • Others presume you have other health problems    | 7 23.3           |

### Table 4. Subjective assessment of the 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 |

In this study, after the data was collected, the Shapiro-Wilk normality test was carried out, which showed the EMIC and the WHOQOL-BREF score 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 correlation between perceived stigma and quality of life ($p=0.011; r=-0.459$) indicated a negative correlation with moderate correlation strength.

### DISCUSSION

In this study, it can be concluded that the majority of research subjects were aged between 19–40 years old, as many as 20 subjects (66.7%). The result of this study is relevant to previous research by Rahayuningsih, who reported that Leprosy was mostly in the 18–40 years age range as many as 34 people (72.3%). Leprosy can occur at all ages, from 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.

The majority of the subjects of this study were male (70%). This result is relevant to the research conducted by Pane et al., which reported male sex predominance (82.4%). The results of several studies in the world, except in several countries in Africa, also found male sex predominance. 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.

In this study, most research subjects were with senior high school education (70%). This is in accordance with research conducted by Menaldi, who reported that most research subjects were with senior high school education (57.5%). 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. Senior 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, most research subjects with income below the minimum wage in Medan (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 (91.49%). 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
In this study, most research subjects were married (56.7%). This is in accordance with the research conducted by Ibikunle et al., who reported most of the research subjects were married (77.8%). Leprosy can cause social complications in marital relationships. A study in South Africa reported that one-third of leprosy patients had been abandoned by their partners, especially females. However, in their culture and rural patients, women are usually more obedient and prefer to maintain a marriage. 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 (56.7%). The corresponding results were also obtained in a study conducted by Astutik et al., were found with a negative perceived stigma (50.4%). Negative perceived stigma indicates that leprosy patients experience a strong stigma that comes from themselves. This condition must be overcome as it can cause an internalized (self) stigma. In internalized (self) stigma, isolation of the surrounding environment occurs. The perceived stigma profile is obtained by answering the EMIC questionnaire. This shows the dominant factor influencing the perceived stigma experienced by research subjects according to the EMIC questionnaire. The dominant factor that affected the perceived stigma were hiding the disease from others and discussing the disease with the closest 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 (65.9%), had less self-respect (57.8%) and told their closest people about the Leprosy they suffered (40.7%). 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 so that it can be handled properly.

In this study, the subjective assessment of research subjects on quality of life was at most ordinary (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 (75%) in areas with self-care groups and in an area without a self-care group (85%). 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. The overall quality of life was assessed subjectively. Some research subjects tended to feel shy and hesitant in answering questions about their overall quality of life, which could cause differences in their answers. 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 (36.7%). This is different from the research conducted by Ulfa, where most of the research subjects were satisfied with their health conditions in areas with self-care group (45%) and in areas without self-care group (55%). 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. Satisfaction with health conditions is assessed subjectively. Subjects in this study experienced a 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. This is in line with research conducted by Ulfa, who reported in areas with self-care groups, the domain of quality of life that is most affected by Leprosy is the physical domain (65.18±6.01). Whereas in areas without self-care groups, the domain of quality of life that is most affected by Leprosy is the environmental domain (49.38±14.39).9 The largest mean value from each domain indicates the quality of life domain that is the best or the least affected in leprosy patients, whereas the smallest mean value indicates the quality of life domain that is the worst or the most affected. A large standard deviation value indicates that there are more variations in the quality of life domain. On the other hand, a smaller value indicates less variation in answers.16,18 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 life activities and work capacity.16,18 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 a 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.29

In this study, most research subjects with a good quality of life (93.3%). This is different from the results of research conducted by Rahayuningsih, who reported 57.45% of patients with poor quality of life and 42.55% with a good quality of life.18 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 five response scales. The higher the total score indicates, the better the quality of life level.18,29 In this study, most research subjects with a good quality of life were 93.3%. This could show the success of the leprosy management program in Medan. However, there were still research subjects with low quality of life. Research subjects with poor quality of life were 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 for the 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 correlation between perceived stigma and quality of life (p<0.001; r= -0.389), which showed a negative correlation with low correlation strength, but in this study, the perceived stigma factor was said to have a strong correlation at most.31 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 could develop from discrimination from family members, friends or the community.27 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.32,33 The greater the perceived stigma, the lower the quality of life of leprosy patients and vice versa. Although it had a significant correlation, perceived stigma was not the only factor that had a correlation with the quality of life of leprosy patients, but the strength of the correlation was moderate. Thus, the perceived stigma was statistically proven to have a contribution to the quality of life of leprosy patients in Medan.

CONCLUSION

There was a significant, moderate negative correlation between perceived stigma and quality of life among the Leprosy patients.

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AUTHOR CONTRIBUTION

All authors have contributed to all processes in this research, including preparation, data gathering and analysis, drafting and approval for publication of this manuscript.

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CONFLICT OF INTEREST

The authors declare no conflict of interest regarding the publication of this article.
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