

Grade of disability and perceived stigma of leprosy patients: Is there any relationship?

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Abstract

Objective To determine the relationship between the grade of disability according to WHO (World Health Organization) and the perceived stigma of leprosy patients.

Methods Cross-sectional research methods with consecutive sampling were employed by the researchers to analyze 30 leprosy patients in this observational study. On research participants, parameters such as age, gender, type of leprosy, and disability grade using the WHO classification system were assessed. The Explanatory Model Interview Catalogue (EMIC) score was used to evaluate perceived stigma. The One-Way Anova test is used to examine the relationship between the WHO disability grade and perceived stigma in leprosy patients.

Results The result of this study is that there is no significant relationship between the grade of leprosy disability and perceived stigma, $p=0.752$. The majority of these studies participants are between the ages of 19 and 40, male, multibacillary leprosy, grade 0 leprosy disability, and have a negative perceived stigma.

Conclusion There is no significant relationship between the grade of leprosy disability and perceived stigma.

Key words

Explanatory Model Interview Catalogue; Grade of disability; Leprosy; Perceived stigma.

Introduction

Mycobacterium leprae causes leprosy, a chronic infectious illness that continues to create major health, sociological, financial, culture, defense, and regional security concerns.¹⁻³ Leprosy deforms and disables people, yet it seldom kills them. These deformities elicit a wide range of reactions in the individual, his or her family, and the general community, including rejection, hatred, fear, stigma, discrimination, and finally socioeconomic degradation.^{4,5}

Stigma is an adverse viewpoint and discriminatory actions directed at leprosy patients, making it difficult for them and their families to live a socially supportive life.⁵ Discrimination against leprosy patients can occur in a variety of ways, including the ability to obtain work, worship in places of worship, use mass transportation, find a life partner, and so on. This condition might lead to feelings of dissatisfaction and even suicidal thought. Stigma can also make people hesitant to seek treatment for fear of being judged by their peers.^{3,6} Of course, this will result in the continuation of the leprosy transmission chain, as well as the onset of handicap in the individual in question, creating an unsolved vicious circle.^{3,5}

Stigma comes in three forms for leprosy

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patients: internalized, perceived, and enacted stigma.^{2,3,7,8} Thoughts, expectations, worries, and perceptual understanding of whatever the public says or may do to them are all manifestations of perceived stigma. Patients suffering leprosy will become unproductive as a result of perceived stigma, and many will become beggars to survive.² In order to assess perceived stigma in certain health problems, a variety of methods are used.⁹⁻¹³ The EMIC questionnaire, which has been used to assess stigma in a variety of health problems, including leprosy, is one of the most widely used instrument.⁸⁻¹³ The goal of this study is to determine if there any relationship between the grade of leprosy disability according to WHO and perceived stigma of leprosy patients.

Methods

A consecutive sampling technique was used to collect 30 leprosy patients visiting the H. Adam Malik Hospital, Dr. Pirngadi Hospital, and Universitas Sumatera Utara Hospital between January and July 2020. This is a cross-sectional study using an analytical method. Patients suffering leprosy, 18 years old or older and willing to sign informed concern were eligible to participate in this study. Patients who refused to cooperate were excluded from the study. This study received permission from the Universitas Sumatera Utara's research ethics committee, located in Medan. According to the World Health Organization, grade 0 disability is defined as having no abnormalities in the eyes, hands, or feet as a result of leprosy. If you have leprosy-related eye damage (corneal anaesthesia, vision >6/60, visual impairment is not severe, and you can still count fingers from a distance of 6 meters), you have a grade 1 disability. There is anaesthesia and muscle weakness in the hands and feet in grade 1 disability, but no obvious disability or damage caused to leprosy. Lagophthalmos, iridocyclitis, corneal opacity, and significant visual abnormalities (vision 6/60,

unable to count fingers from 6 meters away) are all examples of grade 2 eye handicap. The visual damage from leprosy is grade 2 disability in the hands and feet (ulcers, claw fingers, and claw toes). The EMIC score was used to assess the perceived stigma. The data was then evaluated with a computer program using the One-Way Anova test to see if there was a relationship between the WHO disability grade and perceived stigma of leprosy patients.

Results

Table 1 displays the characteristics of the study participants in this study.

In this study, the total EMIC score was 13.23 ± 7.89 on average, with a median of 14. The median value was taken as a cut-off point, resulting in 17 people (56.7%) having a negative perceived stigma and 13 persons having a positive perceived stigma (43.3%). In recent study, most subjects were with negative perceived stigma (**Table 2**).

The Shapiro-Wilk normality test was conducted to assess the relationship between leprosy disability and perceived stigma, which showed

Table 1 Characteristics of the study participants.

Characteristics	Frequency (n=30)	
	n	%
Age (years old)		
19 – 40	20	66.7
41 – 62	8	26.7
63 – 84	2	6.7
Sex		
Male	19	61.3
Female	11	35.5
Leprosy type (WHO)		
Paucibacillary	3	10
Multibacillary	27	90

Table 2 Perceived stigma based on EMIC.

Perceived stigma	n	%
Positive	13	43.3
Negative	17	56.7
Total	30	100.0

Table 3 The relationship between the grade of leprosy disability and the perceived stigma of leprosy patients

Grade of leprosy disability	n (%)	p-value
Grade 0	26 (86.67)	0.752
Grade 1	3 (10)	
Grade 2	1 (3.33)	

an EMIC score to measure the perceived stigma of leprosy patients and the distribution is normal. The results of statistical using the One-Way Anova test at the level of significance set at $\alpha \leq 0.05$, obtained result of $p=0.752$ on 30 research participants indicated no significant relationship between the grade of leprosy disability and perceived stigma (**Table 3**).

Discussion

Leprosy is more frequent in productive ages, which is around 20-30 years.^{1,14} Leprosy is a disease which often affects men. Social, cultural, and educational aspects all play a role in this. Because men are more mobile, they are more likely to be exposed to leprosy infection sources. Because MB type leprosy has more leprosy bacilli, it is more infectious and has a higher risk of transmitting leprosy.¹⁴

Failure to incorporate activities linked to disability prevention using basic technology and patient motivation into leprosy management accounts for a significant amount of the disability burden. The public associating leprosy with deformity and disability in areas where it is prevalent. The public perceives the failure of control programs to handle the problem of deformity as a failure to treat the disease.⁵

The terminology "leprosy disability" refers to any injury or restriction of a person's activities. There are three aspects in disability namely impairment (injury to function or structure), activity restrictions and difficulty with interaction. The impairment level of new leprosy patients must be determined. The grade of

disability was determined by evaluating the eyes, hands, and feet, with the highest disability rate determining the patient's disability grade (general disability grade).^{1,15}

Positive (low total EMIC score) and negative (high total EMIC score) perceived stigma are assessed using the median value of the total EMIC score as the cut-off point. The majority of the research participants have a negative perceived stigma, according to the findings of this study. Negative perceived stigma indicates that leprosy patients are subjected to intense stigma from themselves, which must be addressed so that they do not develop internalized (self) stigma, which drives leprosy patients to withdraw themselves from their surroundings.^{2,14,16,17}

Perceived stigma refers to a stigma that is perceived by leprosy patients. Negative stereotypes cause feelings of devaluation, humiliation, secrecy, and retreat. It might be caused by intolerance from relatives, peers, or societies. As a result of enacted and perceived stigma, patients being more aware of what people think and say about them, causing anxiety and negative image about themselves, which lead to internalized stigma.^{2,7}

According to the International Federation of Anti-Leprosy Associations, the EMIC questionnaire was used to examine perceived stigma in leprosy patients.^{9,11-13} Higher EMIC score is incoherent with the level of perceived stigma.^{9,16,17} Each item on the EMIC questionnaire corresponds to a particular facet of perceived stigma. By defining the profile of leprosy patients, the EMIC questionnaire can also examine the primary elements that influence their perceived stigma.¹⁶ The EMIC questionnaire was created to assess disease-related attitudes and perceptions. The EMIC questionnaire, which has 15 items about leprosy

stigma, has been verified and has a high level of reliability.^{9,13}

No significant relationship between the grade of leprosy disability and perceived stigma was found in this study. This is in accordance with Adhikari *et al.* who found there is no statistically significant difference in perceived stigma for leprosy disability grades 0.1 and 2.¹⁶ According to Astutik *et al*; there is a relationship between perceived knowledge of leprosy and perceived stigma based on disability grade. Subjects with a grade 2 disability and a negative knowledge perception are more likely to be stigmatized. However, because education was found to be the most impactful factor on perceived stigma in this study, programs focusing on health education should be able to rectify misconceptions and raise awareness of perceived stigma in leprosy patients.²

There are many factors associated with perceived stigma in leprosy patients. Lower education level, perceived economic inadequacy, obligation to change the occupation due to leprosy, lack of knowledge and the wrong perceptions about leprosy, the presence of visible deformities, ulcers and disabilities were the significant factors contributing to higher levels of perceived stigma in leprosy patients.¹⁶

Conclusion

No significant relationship was found between the grade of leprosy disability and perceived stigma in this study. However, most research subjects in the 19-40 years age group, male, multibacillary form leprosy, WHO grade 0 leprosy disability, and most research subjects have a negative perceived stigma.

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