Mixed Methods Analysis: Traditional Medication,Stigma, and Leper's Family Support Roles in Level II Leprosy Disability

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Abstract

People with a level II leprosy disability have limited functions in society. In Nagan Raya District, there is a 41% leprosy endemic area with a 5% level II disability rate. The goal of this research was to prove the relationships of traditional medication, stigma, and leper's family support to level II leprosy disability. This research used mixedmethodsand a case-control design with 84 respondents42 case respondents (level II leprosy disability) and 42 control respondents (level 0 leprosy disability)chosen by consecutive sampling under some inclusion and exclusion criteria. Data collection used the in-depth interview method. This study used bivariate data analysis with the chi-square test and multivariate data analysis with the logistic regression test and the Miles and Huberman's model. The results of the chi-square analysis indicated that traditional medication had p value=0.014 (OR: 2.3; 95% CI: 0.2–7.7), stigma p=0.04 (OR:3.6;95% CI: 1.5–8.9), and family's support p=0.192 (OR:2.0; 95% CI: 0.7–5.8). The results of the logistic regression analysis showed that stigma was a risk factor for leprosy level II disability with p value=0.006, (OR=4.9; 95% CI: 1.6–15.1) and probability of 99.96%. Based on the interview results, lepers were feeling uncomfortable with the society's not acceptingthem in a good way. This was especially the case with khanduri(feast) when it came down to food in that the society assumed lepers would transmit the infectious, disgusting disease. The Nagan Raya District Health Office is expected to encourage the societyto accept lepers and provide information regarding the process of leprosy transmission so as to appease the community's fearand to prevent further disability.

Keywords: *disability, family's support, leprosy, level II, mix methode, stigma, traditional medication.*

Introduction

Level II disability has become a significant problem for lepers, almost all of whomexperience limitations in their function within the society and work environment due to rejection and stigma. (1) (2)

The disability of leprosy is characterized by peripheral nerve damage during the leprosy reaction (sensory, motor, and autonomic). (3)Anesthetics and anatomical abnormalities in the hands and feet are often found in this condition. This disability is also characterized by corneal anesthesia, lagophthalmos, and severe visual disturbances. (4) Leprosy disability due to peripheral nerve damage occursin several stages. The first one is the stage of involvement where nerve thickening and anesthesia or muscle weakness occur. Then, there is the stage of damage when nerve damage and dysfunction occur, and muscle weakness shows that the nerve has been damaged or has experienced paralysis. The last one is the stage of destruction when the nerve has been permanently and completely damaged. (5)

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The disability of a patient's organs makes the patient psychologically, socially, and economically disturbed. The prevalence of leprosy in 2014 was 0.79 of 10,000 population. The level II disability rate in 2013 was 6.82 and in 2014 6.33 of 1,000,000 populations. The level II disability rate in Aceh Province in 2014 was 1.4 of 100,000 population,[7]while in 2015, Nagan Raya Regency had a 41% leprosy endemic area with 64 cases of level II leprosy disability. [8]

Leprosy defects occur through direct infiltration of *Mycobacterium leprae*into the peripheral nerve fibers in the eyes, feet, and hands, with leprosy reactions due to the cellular immune's great responses in the form of changes in the skin and nerve inflammation. The skin generally increases active lesions or raises new lesions that result in an inflammatory response in the affected skin and nerve region. The inflammation of the nerve tissue could cause damage and disability. The delay in the early discovery of patients and in the treatment would increase the risk of leprosy disability. [6]

Late diagnosis could generate significant physical disability. The damage is not limited to physical inability;it also creates a negative image that leads to discrimination and social stigma toward individuals and families. [9] The main risk factor for leprosy disability is being late in providing appropriate care. Some other risk factors are multiple nerve thickening, leprosy type (PB or MB), and age. [10]

The results of prior related research conducted in Brazil stated that nerve thickening, age <15 years, MB leprosy type, and low education with ORs 8.4, 7.0, 5.7, and 5.6, respectively,became risk factors for leprosy disability. Related research was also conducted in Indonesia,which investigated the risk factors for level 2 disability. The results of this study showed that type of leprosy (OR = 5.9), leprosy reaction (OR = 9.4), regularity of treatment (OR = 0.1), and age (OR = 6.4) acted as risk factors for disability of level II leprosy. [11] [12]

Another related research study is entitled "The Effectiveness of Traditional Healers in Program to Control Leprosy in Nagan Raya District in Aceh." The results of the study showed that there was a significant difference in knowledge about leprosy between EG (experimental group—*tabibs* after training and provision of a pocketbook) and CG (control group—*tabibs*who did not get any training nor pocketbook). After the training, there were also significant differences in attitude toward leprosy and in the future role of *tabibs*in controling the spread of leprosy between the EG and the CG. [13]

The objective of this study was to demonstrate risk factors of traditional treatment, stigma, and lack of leper's family supportfor the occurrence of level II leprosy disability. Various programs have been carried out for leprosy control, such as,multidrug therapy (MDT) and BCG vaccination; however, the disability rate remains high. There are also some other risk variables that have not been studied in Nagan Raya District, such as, individual characteristics and the existence of traditional leprosy treatment. Therefore, the researchers sought to know the various risk factors for level II leprosy disability in Nagan Raya District, Aceh Province.

Literature Review

Leprosy is a chronic skin disease that attacks the outer nerve. *Mycobacterium leprae*, an acid-resistant bacterium, can cause this disease. In the worst condition, leprosy would spread to other organs such as the mucosa, kidneys, skin, testicles, and eyes if there is no proper treatment. This condition would cause physical limitations and dysfunction in family and society. [14]

Disability is a term used to cover three aspects: impairment, activity limitation, and participation problem. [6]Leprosy disability is characterized by peripheral nerve damage when leprosy reaction occurs (sensory, motoric, and autonomic). [3]This disability is characterized byanesthetics and anatomical abnormalities in the hands and feet, as well ascornealanesthesia,lagoftalmos, and severe visual disturbances. Itcan be classified into primary and secondary disability. Primary disability is caused directly by disease activity, especially the damage due to the tissue response to *Mycobacterium leprae*. Meanwhile,secondary disability is mainly due to the damage to the sensory, motor, and autonomic nerves. [4]

The World Health Organization (WHO) classifies leprosy disability into three levels by categorizing the

eyes, hands, and feet. An absence ofanesthesia and anatomical abnormalities characterizes level 0. Level I is marked by anesthesia, but with no anatomical abnormalities.There are alsoeyeabnormalities, but they are not visible;vision is slightly reduced. Then, level II is characterized by anatomical abnormalities. There is lagoftalmos in the eyes, and the vision is very disturbed. (4)

Level II disability becomes a big problem for lepers, almost all of whomsuffer from function limitations in the society and work environment due to rejection and stigma. (1) (15) (2)Leprosy disability occurs through direct infiltration of *Mycobacterium leprae* to the peripheral nerve structures in the eyes, feet, and hands with leprosy reaction where sudden great cellular immune response exists in the form of skin changes and nerve inflammation. On the skin, lesions generally become more active or bring up new injuries resulting in an inflammatory response in the affected skin and nerve area. Inflammation of the nerve tissue can cause damage and disability. (6)

Methods

This study used mixedmethodsand a case-control design.In this study, the risk factors were studied retrospectively in the case group (level II leprosy sufferers) and the control group (level 0 disabled persons) in Nagan Raya District in July–August 2017. The population of this study was level II sufferers and level 0 (non-disabled) people affected by leprosy recorded at the Nagan Raya District Health Office until May 2017, from whom a sample was extracted under some inclusion and exclusion criteria. Sampling was conducted by a non-probability sampling method using consecutive sampling, whereby case groups and control groups were sampled based on a sequence of secondary data, starting from the latest data to the required number of sample units.

The sample of this research was composed of 84 items: the first 42 in the case group and the next 42 in the comparative group. The sample was obtained from a sample size calculation by considering *the odds ratio* of previous research results.

In this study, various risk factors for level II leprosy disability were described by several variables, namely, traditional medicine, stigma, and lack of family support.

This study used bivariate data analysis with a chi-square test to analyze all of the variables researched and multivariate data analysis with logistic regression analysis aided by a computer program.

Then, the results of the independent interview were analyzed by Miles and Huberman's model in three stages, namely, data reduction, data display, and conclusion drawing/verification.

Results and Discussion

Table 1: Respondents' Characteristic Distribution

Respondents' Characteristics	Level II Disability		Level 0 Disability	
	n = 42	(%)	n = 42	(%)
Age				
- 1–25 years old	6	14.3	19	45.2
- 26–45 years old	23	54.8	16	38.1
- > 46 years old	13	31.0	7	16.7
Gender				
- Male	27	64.3	25	59.5
- Female	15	35.7	17	40.5

Cont... **Table 1: Respondents' Characteristic Distribution**

	Level of Education				
-	Not attending school	7	16.7	5	11.9
-	Elementary school/ equivalent graduate	10	23.8	4	9.5
-	Junior high school/equivalent graduate	7	16.7	3	7.1
-	Senior high school/equivalent graduate	12	28.6	24	57.1
-	University graduate	6	14.3	6	14.2
	Occupation				
-	Unemployed	8	19.0	17	40.5
-	Civil/Military service	1	2.4	1	2.4
-	Entrepreneurship	8	19.0	9	21.4
-	Farming	25	59.5	15	35.7
	Marital Status				
-	Single	19	45.2	16	38.1
-	Married	23	54.8	26	61.9

Table 1 shows a description of the determinant variables of the study: in the level II disability category, 54.8% of the respondents were 25–46 years old, 64.3% were male, 28.6% were of a high school education level, 59.5% were engaged in farming professions, and 54.8% were of a married status.

Bivariate analysis was intended to figure out theodds ratios (OR) of the risk factors (independent variables) for level II leprosy disability (dependent variable); it was conducted at a significance level of 95%. The distribution of the risk factors for level II leprosy disability can be seen in complete in the following table:

Table 2: Odds Ratiosof the Case and Control Groupsof Level II Leprosy Disability

Variable	OR	95% CI	p
Low education level	3.3	1.3–8.2	0.008
Type of work	2.4	1.0–5.9	0.046
Lack of family support	2.0	0.7–5.8	0.192
Traditional treatment	3.1	1.2–7.7	0.014
Leprosy stigma	3.6	1.5–8.9	0.004

Table 2 shows the variables that were statistically related to level II leprosy disability: education level, type of work, traditional treatment, and leprosy stigma.

The variables that became candidates for the logistic regression test were those that in the bivariate analysis had p-values<0.25, including level of education, type of work, traditional treatment, and leprosy stigma. The results of the multivariate analysis showed that there were two independent variables that proved to be statistically risky, namely, low education level and leprosy stigma. The results of the multivariate analysis can be seen in the following table:

Table 3: Results of Logistic Regression Analysis of Level II Leprosy Disability Risk Factors

Variables	OR	95% CI	p
Low education level	3.4	1.1–10.9	0.038
Leprosy stigma	4.9	1.6–15.1	0.006

Table 3 indicates that out of the five variables simultaneouslyanalyzed, two variables were proven to be risk factors for level II leprosy disability. The results of the multivariate analysis showed that low education level posed 3.4 times the risk posed by higher education level,and leprosy stigma posed 4.9 times the risk posed by an absence of leprosy stigma,for level II leprosy disability.

Level of education was related to lepers' act of treatment seeking. Patients with low education levels tend to be slow in seeking treatment and in diagnosing the disease. This issue could lead to the exacerbation of their disability. Several studies have found that level of education was related to leprosy disability. Low level of education could affect lepers' not treating the leprosy-related wounds, causing the worsening ofthe condition of the disability. [16]

The results of the multivariate analysis showed that low education level posed 3.4 times the risk of higher education level for the occurrence of level II disability with p = 0.038 and OR = 3.4 (95% CI: 1.1–10.9). This research's resultsare in line with those of previous research on leprosy disability: the roles of impairment, activity, social participation, stigma, and discrimination in Indonesia yielded lower results, with lower education levels being associated with leprosy disability, p = 0.001. [9]

Stigma is a "sign" marked by community on someone. Stigmatized people behave as if they are in an embarrassing or tainted name. [17]Self-stigmatization of lepers is very real. People with leprosy can be ashamed, maybe because of their attitude and disability. This attitude could isolate them from society. Thus, the opinion that leprosy is disgusting, shameful, and requiring covering up will be a real stigma for sufferers. [18]

The results of the multivariate analysis further showed that leprosy stigma posed 4.9 times the risk posed by an absence of stigma for level II leprosy disability with p = 0.006 and OR = 4.9 (95% CI: 1.6–15.1). To avoid the effects of stigmatization, lepers made various efforts to prevent others from learning or knowing about their illness, including hiding their illness effectively and preventing self-disclosure to the community, family, and friends. [9]

Stigma is something which brings disgrace and shame to someone and makes him/her feel inferior, embarrassed, and afraid of something. Self-stigmatization of lepers is very real. People with leprosy can be ashamed, maybe because of their disability, and this attitude can isolate them from society. Thus, the opinion that leprosy is disgusting, shameful, and requiring covering up will be a real stigma to patients. Sufferers would experience difficulty in interacting. They would isolate themselves, and this attitude will become permanent. [19]

Stigmatization could cause the society/other people to change their perceptions of and behaviors toward individuals who are stigmatized, and generally, cause those who are stigmatized to change their perceptions about themselves and make them define themselves as deviant individuals. [17]

This research is in line with previous qualitative research on the factors underlying patients' perceptions of the stigma of leprosy. Leprosy sufferers perceived that the community around their residence and friends did not know that they were experiencing leprosy. The sufferers assumed that their neighbors and friends thought that they suffered other disabilities such as diabetes, neurological diseases, or allergic diseases from taking wrong medications. Their perception related

to self-limiting attitudes was that covering up their disability was an action to overcome stigma. [17]

In-depth Interview:

1st Respondent

(58 years old)

""People treat me normally, but I feel uncomfortable to blend with the people. If there is a religious event that serves food, I rarely partake in eating, and if there is an event that requires me to give food, I will not do so. I am afraid that people will feel disgusted to eat food from my family. When praying together, I always stand up at the end of the line, so I would not touch other people."

2nd Respondent

(65 years old)

"I do not blend with people again. I am ashamed of this disease. People are disgusted by me. I only visit a particular neighbour."

3rd Respondent

(51 years old)

"I do not have a wife, but I have a younger sister and an older brother. However, they ignore me. They are busy with their activities and families. Maybe they do not want to accept me. My mother passed away a long time ago, and my marriage was canceledbecause of my leprosy. Now I live alone. I work as a farmer and sell vegetables."

4th Respondent

(19 years old)

"My mother and older sister are taking care of me. They do not avoid me because my disease is not severe yet. My doctor just suggested I consume medicines. My disease is just common. I feel itchy, and there are rashes and white patches on my body."

5th Respondent

(49 years old)

"I knew that this was leprosy when I got treatment from the doctor. The doctor said that this is leprosy. This verdict made me ashamed and caused me to stop the treatment. I feel ashamed to be called as a leper because I am an Imam. Another doctor said that I suffer a common skin disease."

The limitation of this study is that it did not involve any bacteriological examination and monitoring on level 1 disabled people.

Conclusion

Based on the results of the study, it can be concluded that two variables were proven to be risk factors for level II leprosy disability, namely, low education level with p = 0.038 and OR = 3.4 (95% CI: 1.1–10.9) and leprosy stigma p = 0.006 and OR = 4.9, (95% CI: 1.6–15.1). The probability calculation results showed that the two variables that were proven to pose risks had a 99.96% chanceof causing level II leprosy disability. The Nagan Raya District Health Office is expected to supervise the risked population of low education levels and provide leprosy sufferers with an understanding to discourage a sense of inferiority in them and build an atmosphere in the familiesthat will prevent them from staying away from the community. Then, the community is expected not to isolate lepers, but embrace them to continue their integrity with the community to obtain information and proper health services. Further research was carried out with a bacteriological examination on level II and level I disability. The limitation of this study was that it did not carry out any bacteriological examination and monitoring on level 1 disabled people.

Conflict of Interest: The authors declare that they have no conflict interests.

Ethical Issue: Ethics clearance was obtained from the Ethics Committee of Karyadi Hospital, Semarang, Indonesia, with study protocol code No. 724/EC/FK-RSDK/2016. Before conducting a further interview, the respondents were asked to provide informed consent through a form of consent.

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