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## The relationship of knowledge, family support and stigma WTH the quality of life in Lima district

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### Abstract

Leprosy is a disease problem in Indonesia, ranked third with the highest number of cases in the world, a complex condition involving physical health and quality of life of patients. Quality of life is closely related to knowledge, family support and stigma, where these factors can affect the quality of life. The purpose of this study was to analyze the relationship between knowledge, family support and stigma with the quality of life of people with leprosy in Lima Pulu Kota District. This research is an observational study, using a cross sectional research design. The study population was 45 people so that the research sample was taken by total sampling, that is, all populations were used as research

samples. Data collection used secondary data in the form of a list of leprosy patients and primary data was obtained by means of a questionnaire. The data analysis method includes univariate analysis and bivariate analysis using simple logistic regression tests. The analysis showed that knowledge ( $p < 0.001$ ), family support ( $p = 0.024$ ) and stigma ( $p = 0.034$ ) had a significant relationship with the quality of life of people with leprosy in Lima Pulu Kota Regency. Efforts to increase knowledge by providing IEC (communication, information and education), providing motivation and full support in carrying out medication, self-care so that the quality of life of people with leprosy will be better.

**Keywords:** Knowledge, Family Support, Stigma, Quality of Life, Persons with Leprosy

### 1. Introduction

One of the public health problems in Indonesia is the leprosy disease, this problem can have a very complex impact. Leprosy sufferers are found in many economically weak communities and in general it is found in many developing countries such as Indonesia, leprosy can be caused by lack of public knowledge, socio-economic welfare and state limitations in providing inadequate health services.

The leprosy germ *Mycobacterium leprae* (*M. leprae*) can cause chronic chronic disease affecting the upper respiratory tract, muscles, eyes and bones and almost all organs of the body, especially the peripheral nervous system, then can attack the skin and mucosa (mouth). People infected with leprosy germs are sub-clinical but some are clinical and can give less good effects where the bacteria can cause disability.

Lima Pulu Kota Regency is an area in West Sumatra Province. Based on the data obtained from the District Health Office Fifty Cities were 45 lepers, typeleprosy patients pausibacillary (PB) as many as eight people (17.78%) and the type of multi-bacillary (MB) as many as 37 people (82.22%).

Leprosy is relatively easy to cure, however, the impact it has on a person's life can last indefinitely because it is permanent due to disabilities, in addition to the resulting disabilities which give a bad stigma. The existence of stigma from the sufferer, lack of knowledge and lack of family support for the sufferer so that it affects the quality of life of the sufferer

There are still people with leprosy in Fifty Cities District due to a lack of knowledge about leprosy so that the disease can cause physical changes in the sufferer and lack of family support for the sufferer so that affect the quality of life of people with leprosy. So based on the above background, the researcher wants to analyze the relationship between knowledge, family support and stigma with the quality of life of people with leprosy in Fifty Cities District

### 2. Research Methods

This research is an study observational, using a research design cross sectional. The population in this study were 45 people affected by leprosy in Lima Pulu Kota Regency so that all patients were used as a total sampling. The independent variables of this study are knowledge, family support and stigma, while the dependent variable is the quality of life of people with leprosy.

Data collection uses secondary data in the form of a list of leprosy patients obtained from the Health Office and primary data is obtained using a questionnaire. This study used four questionnaires, namely knowledge, family support, stigma and quality of life. The stigma questionnaire, quality of life was adopted from EMIC-AP and WHOQOL-Bref which has been translated into Indonesian. While the questionnaire for knowledge and family support was tested for validity and reliability first (Tambunan *et al.*, 2018) [16], knowledge instruments, family support were validated for 20 people with leprosy. Data analysis methods include univariate analysis and bivariate analysis using simple logistic regression. This research was conducted in April 2020.

**3. Results and Discussion**

**3.1 Univariate Analysis**

**Table 1:** Frequency Distribution of Respondent

No	Characteristics of Respondent	Frequency	Percent
1	<b>Gender</b>		
	Female	25	55,6
	Male	20	44,4
2	<b>Age</b>		
	Young People and Adults	21	46,7
	Old People	24	53,3
3	<b>Education</b>		
	Higher education level (SMA, D3 and S1)	20	44,4
	Low education level (SD dan SMP)	25	55,6
4	<b>Marital Status</b>		
	Married	24	53,3
	Not Married	21	46,7
5	<b>Income</b>		
	High	16	35,6
	Low	29	64,4

Based on table 1 above, it is known that the characteristics of the majority of respondents are female 25 respondents (55.6%), the most age group is at the age of parents 24 respondents (53.3%), low education level 25 responsive (55.6%), the majority of married status was 24 respondents (53.3%) while respondents with low income were 29 people (64.4%).

**3.2 Bivariate Analysis**

**Table 6:** Relationship between Knowledge and Quality of Life of by Leprosy

No	Knowledge	Quality Of Life				Total		RP (95% CI)	p
		Less		Good		n	%		
		n	%	n	%				
1	Less	21	80,8	5	19,2	26	100	11,760 2,865-48,268	<0,001
2	Good	5	26,3	14	73,7	19	100		

Based on the results of the study by conducting bivariate analysis to prove the relationship between knowledge and quality of life, was carried out using simple logistic regression statistical tests at the 95% confidence level,

namely ( $\alpha = 0.05$ ) obtained a value  $p < 0.001$  less than 0.05 and a RP value of 11.760 (95% CI = 2.865-48.268), which means that there is a significant relationship between knowledge and the quality of life of people with leprosy.

**Table 7:** Relationship between Family Support and Quality of Life of Leprosy

No	Family Support	Quality Of Life				Total		RP (95% CI)	p
		Less		Good		n	%		
		n	%	n	%				
1	Did Not Get Support	17	73,9	6	26,1	23	100	4,093 1,160-14,433	0,024
2	Get Support	9	40,9	13	59,1	22	100		

**Table 2:** Distribution of Knowledge Frequency

No	Knowledge	Frequency	Percent
1	Good	19	42,2
2	Less	26	57,8
	Total	45	100

Based on Table 2 above, it can be seen that there are more knowledge of people with leprosy who have less good knowledge, namely 26 people (57.8%) and less with good knowledge as many as 19 people (42.2%).

**Table 3:** Frequency Distribution of Family Support Family

No	Family Support	Frequency	Percent
1	Support	22	48,9
2	No Support	23	51,1
	Total	45	100

Based on Table 3 above, it can be seen that the support for families with leprosy is mostly without getting support. Support, namely as many as 23 people (51.1%) and less by getting support, namely as many as 22 people (48.9%).

**Table 4:** Stigma Frequency Distribution

No	Stigma	Frequency	Percent
1	Weak	25	55,6
2	Strong	20	44,4
	Total	45	100

Based on Table 4 above, it can be seen that the stigma of leprosy sufferers is more by having a weak stigma, namely 25 people (55.6%) while the least with strong stigma were 20 people (44.4%).

**Table 5:** Frequency Distribution of Quality of Life

No	Quality of Life	Frequency	Percent
1	Good	19	42,2
2	Less	26	57,8
	Total	45	100

Based on Table 5 above, it can be seen that the quality of life of people with leprosy is more with less quality of life. Good, namely as many as 26 people (57.8%) while the least with a good quality of life were 19 people (42.2%).

Based on the table above, the value *pis* equal to 0.024 less than 0.05 with a RP value of 4.093 (95% CI = 1,160 to 14,433) which means there is a significant correlation

between family support with the quality of life of persons affected by leprosy in Fifty Cities District.

**Table 8:** Relationship between Stigma and Quality of Life of Persons with Leprosy

No	Stigma	Quality Of Life				Total		RP (95% CI)	p
		Less		Good		n	%		
		n	%	n	%				
1	Strong	15	75,0	5	25,0	20	100	3,818	0,034
2	Weak	11	44,0	14	56,0	25	100	1,058-13,784	

Table 8 above the value *pis* shows that equal to 0.034 ( $\alpha = 0.05$ ), which shows that there is a significant relationship between the stigma factor and the quality of life of people with leprosy in Fifty Cities District. From the analysis results, the value of RP 3.818 (95% CI = 1,058 to 13,784)

From table 6, it is found that the value  $p < 0.001$  is less than 0.05 and the value of RP 11,760 (95% CI = 2,865-48,268) shows that there is a significant relationship between knowledge and the quality of life of people with leprosy in Lima Pulu Regency. City. Referring to the statistical results, it can be explained that people with leprosy who have good knowledge will be able to affect the quality of life of people with leprosy. This is supported by research conducted by Singh (2019) [15] which shows the same results from the research conducted, where the majority of respondents have good knowledge ( $p = 0.001$ ), this is also in accordance with Rahmadani's research (2016) the level of knowledge has a significant relationship to quality of life, the better the respondent's knowledge, the better the quality of life of the respondent, and conversely the less good the knowledge, the lower the quality of life of the respondent.

The results of this study are in accordance with Green's theory which states that someone who is highly knowledgeable will be more likely to behave well in the health sector, seek treatment and take preventive measures so that the disease does not become a complication with other diseases and can improve the quality of life. Even though the characteristics of education are a factor related to the level of knowledge about leprosy, the results of the analysis in this study show that there is a significant relationship with the quality of life of people with leprosy. Knowledge possessed by a person will raise awareness of that person in maintaining his health. Knowledge itself is influenced by education, for people with high levels of education, the knowledge is also getting better. Based on the analysis, the value *pi* equal to 0.024 less than 0.05 with a value of RP 4.093 (95% CI = 1.160 to 14.433) which means there is a strong correlation. There is a significant difference between family support and the quality of life of people with leprosy in Lima Pulu Kota District. The majority of family support is felt by respondents so that with family support it is able to make people with leprosy more valued so that it affects the quality of life of people with leprosy, this is in line with the research of Refitlianti (2017) [13]. There is a significant relationship between family support and the quality of life of people with leprosy with a p value equal to 0.001, which states that the greater the family support, the better the quality of life for people with leprosy, the quality of life for people with leprosy is influenced by several factors, one of which is family support, where the better the dukun Bro, family, the better the quality of life and vice versa, the less family support, the less the quality of life for people with leprosy

This research is the same as Muna's research (2019) at the

Jepara District Hospital with a p value of 0.001 smaller than 0.05, which states that there is a relationship between the respondent's family support and the quality of life of people with leprosy, Friedman (2010) explains that the effective function of the family is a basic aspect in forming and achieving family harmony, affection and recognition from family members will provide a comfortable feeling and increase the self-esteem of lepers. Family support has a positive influence on the future of leprosy sufferers, so that the greater the family support, the better the quality of life for people with leprosy. Families are expected to exist so that they will always try and be enthusiastic in efforts to improve their health and quality of life.

Based on the stigma table, the value *pi* equal to 0.034 ( $\alpha = 0.05$ ), indicating that there is a significant relationship between the stigma factor and the quality of life of people with leprosy. From the analysis, it was obtained that the value of RP was 3.818 (95% CI = 1.058 to 13.784). The stigma that comes from the sufferer is fear and worry about discrimination, rejection, job loss, physical harassment and divorce that someone feels because of something they have suffered. Stigma is a phenomenon that can have quite a broad impact, which can disrupt a person's life. The research is in line with Hidayati's research (2019) which shows that stigma has a significant relationship with the quality of leprosy with a value ( $p = 0,000$ ) smaller than  $\alpha = 0.05$ . The leprosy stigma is one of the factors that causes delays in patients getting treatment (Wong, 2004) [17]. This is because people with leprosy often hide their condition as leprosy sufferers and are reluctant to go to health services regularly, this situation does not support the process of treatment and healing, on the contrary, it will increase the risk of disability for the sufferer himself.

Stigma can have a psychosocial impact on the sufferer, besides the disability condition experienced by leprosy sufferers can also physically disturb the patient to carry out normal activities. With the physical changes experienced by leprosy sufferers can affect socially in addition to the shame and insecurity of dealing with others, people who see physical changes in leprosy sufferers tend to feel afraid and choose to avoid and alienate the sufferer and sufferers tend not to be appreciated by the environment in which he lives so that it can affect the quality of life of people with leprosy. The higher the sigma received by the sufferer can affect the lower quality of life of the sufferer and vice versa if the stigma experienced by the sufferer is low or the sufferer does not feel and experience stigma, the patient's quality of life will be good.

**Conclusion**

From the results of the study it can be concluded that there is a relationship between knowledge, family support and stigma in Fifty Cities District. The variable that most contributes to

the quality of life of people with leprosy is knowledge, where knowledge of lepers can provide an overview of the relationship 3 times greater with quality of life. Lepers. This means that the better the knowledge of a person affected by leprosy, the better the quality of life of people with leprosy in Lima Puluh Kota Regency.

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