

## ORIGINAL ARTICLE

## DETERMINANT FACTORS THAT AFFECT THE QUALITY OF LIFE OF PEOPLE WITH LEPROSY IN SUMENEP, INDONESIA

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## ABSTRACT

*Leprosy is a potentially debilitating disease, that affects patients beyond medical conditions due to its potential impact on mobility, relationships with others, marriage, work, and social activities. The objective of this study was to know the quality of life of leprosy persons in Sumenep regency, Madura, and identify what factors affect the quality of life of people with leprosy. The study was a cross-sectional study involving 110 people with leprosy at Poteran Island, Sumenep regency, in 2017. We used a pre-designed questionnaire to evaluate demographics, attitude, knowledge, perceived stigma, and family support. The quality of life was assessed using a short version of the WHO Quality of Life Assessment, the WHOQOL-BREF questionnaire, which consisted of four dimensions: physical health, psychological conditions, social relations, and environmental conditions. These four domains were summed to get the overall quality of life. Chi-square and logistic regression analyses were performed using SPSS V 23 software using p-value and PR (Prevalence Ratio). About 55.5% of respondents had impaired quality of life. Stigma was a more dominant factor that affected the quality of life followed by knowledge, income, family support and age with POR 10.26, 8.17, 7.37, 7.31, and 4.10, successively. We suggest that to improve the quality of life of people affected by leprosy, it is necessary to deal with stigma through counseling, group therapy, and physical and occupational rehabilitation. Health promotion activities should be directed at empowering families and the community to play an active role in changing people's behavior and modifying the social environment as well as maintaining and improving general health.*

Keywords: *leprosy; quality of life; perceived stigma; health knowledge.*

## INTRODUCTION

Leprosy is a chronic infectious disease caused by the *Mycobacterium leprae*, also known as Hansen's disease. It primarily affects the skin and peripheral nervous system, mucosal surfaces of the upper respiratory tract, and the eyes. Leprosy is a leading cause of permanent disability among infectious diseases; it can lead to deformities, sometimes irreversible, if not treated in time<sup>1-5</sup>. Most cases of leprosy (more than 90%) are concentrated in developing countries<sup>6</sup>. Besides India and Brazil, Indonesia is one of the top three countries with the highest new leprosy cases globally. These three countries contribute as much as 80.2% of new leprosy cases worldwide<sup>4</sup>. Although leprosy could occur at all ages ranging from infancy to very old age, this disease is curable, and treatment in the early stages can prevent disability.

Visible deformities and disabilities associated with leprosy contribute to the stigma and discrimination, even post-disease. Leprosy, if left untreated, can gradually lead to physical disability, psychological burden, and social isolation<sup>2-3</sup>. The stigma associated with leprosy makes leprosy persons delay

seeking appropriate care until they end up with physical disabilities<sup>7-8</sup>. In addition, stigma on leprosy negatively affects the quality of life of leprosy persons due to affected mobility, relationships with others, marriage, work, social activities, and free time<sup>9</sup>. Today, there are new demands for therapy beyond the biomedical aspect, which involves eliminating the stigma of leprosy, encouraging social reintegration, and improving the quality of life related to human rights and humanitarianism. This movement aims to break the traditional model of exclusion/separation of leprosy patients towards a more complete and humanly model<sup>10</sup>.

Indonesia has achieved leprosy elimination (leprosy prevalence <1 per 10,000 inhabitants) in the year 2000. East Java province, which used to have high leprosy cases had also achieved leprosy elimination in 2017. However, ten districts/cities within East Java province have not yet reached eliminations, including Sumenep district<sup>11</sup>. This area in Sumenep has had the highest number of leprosy persons in East Java province for several years<sup>11</sup>.

The objective of this study was to know the quality of life of people affected by leprosy at Talango, a

sub-district in Sumenep district, and to identify determinant factors associated with their quality of life.

## METHODS

To achieve the objective, a cross-sectional study was conducted in January 2018 at Talango subdistrict, Sumenep, using a total sampling approach. We collected the relevant data from all people affected by leprosy and recorded in Talango Public Health Center in this subdistrict.

A total of 110 people recorded as affected by leprosy, were contacted and interviewed in either Talango Public Health Center or their homes. Local enumerators who had been previously trained had interviewed the respondents using a pre-structured questionnaire to evaluate their knowledge, attitude, perceived stigma and family support, combined with the World Health Organization Quality of Life Assessment BREF (WHOQOL-BREF) questionnaire to assess their quality of life (QoL). This widely used WHOQOL-BREF questionnaire was a valid measuring instrument ( $r = 0.89-0.95$ ) and reliable ( $R = 0.66-0.87$ )<sup>12</sup>. During collecting the data, the enumerators were supervised by researchers. WHOQOL-BREF questionnaire consists of 26 questions, with two general questions, and the remaining 24 questions were divided into four dimensions: physical health, psychological conditions, social relations, and environmental conditions. Each question uses a 1 to 5 response scale, with a higher score indicating a better quality of life. The way to calculate each domain as follows: domain 1:  $(6 - Q3) + (6 - Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ , domain 2:  $Q5 + Q6 + Q7 + Q11 + Q19 + (6 - Q26)$ , domain 3:  $Q20 + Q21 + Q22$ , and domain 4:  $Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ . Based on WHO guidelines, the sum of each domain (raw score) will be transformed with a score of 4 - 20 or 0 - 100. The greater the score, the higher the quality of life. The four domains were summed to get the overall quality of life. If the score was smaller than the mean, it indicates poor quality of life<sup>13-14</sup>.

The questionnaire on perceived stigma consists of fear and concern about discrimination, rejection, loss of work, physical abuse, and forced divorce that someone feels because of certain conditions they experience<sup>15</sup>.

To analyze associations between quality of life and its determinant factors, the Chi-square test (in bivariate analysis) and logistic regression analysis were performed using SPSS V 23 software producing p-value, POR (Prevalence Odds Ratio) and the 95% confidence interval of POR. Variables with a p value  $\leq 0.25$  were selected from bivariate analysis and

analyzed further in multivariate analysis to get a p value  $< 0.05$ . The ethical approval was obtained from the YARSI University ethics committee with number 269/KEP-UY/BIA/X/2017. Before filling out the questionnaire, the respondents filled in and signed the informed consent.

## RESULTS

A total of 110 leprosy persons participated in the study. Most of them were female (56.4%). The mean age of 47 years  $\pm 18.8$  (SD). Majority (62.2%) did not attend/complete elementary school. All participants had low socioeconomic status (below regional minimum wage). More than half (59.5%) of respondents were married. About 19% of respondents had deformities in grades 1 and 2. The majority had suffered from leprosy for less than three years (85%)

More than half of the respondents (55.5%) were aware that leprosy is an infectious disease. Almost all respondents still do not know that the cause of leprosy is *Mycobacterium leprae* (98.2%) and less than half of them knew the symptoms of leprosy. Only 23.6% of respondents correctly answered that people might acquire leprosy through prolonged and multiple contact with leprosy patients (Table 1). Combining the knowledge scores and using the median as a cut-off point, the percentage of respondents having good knowledge about leprosy was only 31.8%.

Table 2 showed that most respondents agreed and strongly agreed with important attitudes, such as that leprosy is not a curse; it is an infectious disease; it is curable after taking medicine; patients must take medication properly; patients can get along with the community; families watch the patients' medication. More than half of leprosy persons had a good attitude towards leprosy (69.1%) based on grouping and summarizing the attitude values using the median score as the cut-off point. Respondents stated that their family recommended the correct place for leprosy treatment (99.1%) and supervised taking medicine (88.2%). Most of their families also advised them to restock medicine (87.3%), although less than half of them accompanied leprosy patients to the primary health care to replenish the medicine supply (40.5%). However, some families (11.7%) took no action regarding the situation. More than half of their families reminded patients daily to take the medication (64.5%). Most families also provided social support by not prohibiting leprosy persons from interacting with the community (75.7%). More than half of the families supported patients' self-care by helping clean up their wounds (66.4%) and reminding them to wear footwear when they leave the house (82.9%).

Table 3 shows the stigma of leprosy. More than half of the respondents were afraid/worried about being treated differently and rejected by the environment. Most respondents were afraid of being

forced to separate from their couples. For further analysis, we divided stigma into two categories. The result is more than half of respondents feel the existence of stigma (53,6%).

**Table 1. Knowledge concerning Leprosy**

Question	Correct Response n (%)	Incorrect Response n (%)	Don't know n (%)
Leprosy as a chronic infectious disease	61 (55.5)	1(0.9)	48 (43.6)
Cause of leprosy	2 (1.8)	11 (10)	97 (88.2)
Symptoms of leprosy	51 (46.4)	24 (21.8)	35 (31.8)
Communicability to other	87 (79.1)	21 (19.1)	2 (1.8)
Mode of transmission	26 (23.6)	59 (53.6)	25 (22.8)
The consequence of leprosy	43 (39.1)	27 (24.6)	40 (36.4)
Leprosy is curable	108 (98.2)	2 (1.8)	0 (0)
Length of leprosy treatment	67 (60.4)	22 (19.8)	22 (19.8)
The consequence of incomplete treatment	78 (70.9)	30 (27.3)	2 (1.8)
Time to take medicine	105 (95.5)	4 (3.6)	1 (0.9)
The place to get medicine	109 (99.1)	1 (0.9)	0 (0)
The place to get treatment	109 (99.1)	1 (0.9)	0 (0)

**Table 2 Attitude toward Leprosy**

Attitude toward leprosy	Strongly agree n (%)	Agree n (%)	Less agree n (%)	Disagree n (%)
Leprosy is not a cursed disease	34 (30.6%)	49 (44.1%)	18 (16.2%)	8 (7.2%)
Leprosy is an infectious disease	24 (21.6%)	53 (47.7%)	17 (15.3%)	15 (13.5%)
Leprosy is curable after taking medication	46 (41.4%)	57 (51.4%)	6 (5.4%)	-
The patient must take medication properly	39 (35.1%)	70 (63.1%)	-	-
Leprosy is treatable in all health services	26 (23.4%)	44 (39.6%)	30 (27%)	8 (7.2%)
Every two months patient takes the medicine	6 (5.4%)	28 (25.2%)	42 (37.8%)	32 (28.8%)
Leprosy people can get along with the community	28 (25.2%)	73 (65.8%)	5 (4.5%)	2 (1.8%)
Families may touch the leprosy patient	29 (26.1%)	66 (59.5%)	6 (5.4%)	8 (7.2%)
Leprosy is a frightening disease	18 (16.2%)	20 (18%)	32 (28.8%)	39 (35.1%)
Families watch the patient take medication	46 (41.4%)	57 (51.4%)	3 (2.7%)	2 (1.8%)
Leprosy always causes wound	6 (5.4%)	17 (15.3%)	36 (32.4%)	49 (44.1%)

**Table 3. Degrees of Anxiety upon Stigma on Leprosy**

Stigma on Leprosy	Absolutely worry/afraid n (%)	no Quite afraid n (%)	worried/ Very worried / afraid n (%)
- Feeling afraid/worried about being treated differently due to leprosy	51 (46.4%)	48 (43.6%)	11 (10,0%)
- Feeling afraid/worried about being rejected by the environment due to leprosy	46 (41.8%)	47 (42.7%)	17 (15.5%)
- Feelings afraid/worried about losing a job due to leprosy	62 (56.4%)	37 (33.6%)	11 (10.0%)
- Feeling afraid/worried about being harassed/ insulted regarding physical conditions due to leprosy	57 (51.8%)	39 (35.5%)	14 (12.7%)
- Feeling afraid/worried about being forced to separate from the couple due to leprosy	63 (57.3%)	41 (37.3%)	6 (5.5%)

**Table 4. Central Tendencies of Quality of Life based on WHOQOL-BREF Domains**

Quality of Life	Min-Max	Mean	SD	Median	95% CI Mean
Physical Health Domain	13-100	62.5	20.5	63.0	58.6-66.3
Psychological Domain	19-94	50.2	15.8	44.0	47.3-53.2
Social Domain	19-100	60.4	21.4	50.0	56.3-64.4
Environmental Domain	19-94	50.6	13.6	50.0	48.0-53.2
Total	112-357	223.6	62.3	212.5	211.9-235.4

We summed the score quality of life from 4 domains and obtained the mean score of 223.6 ± 62.3 (SD). The minimum quality of life scores was 112, and the maximum score was 357. Our study revealed that the QoL of leprosy persons was lower in the psychological and environmental domains. For further analysis, we used categorical data for QoL

by using the mean as a cutoff, and we found poor quality of life was 55.5%.

Based on bivariate analysis there were significant associations between quality of life and the following socio-demographic factors, i.e., age, knowledge, income, family support, attitude, and stigma (Table 5).

**Table 5. The Association between Quality of life and Its Determinant Factors**

Variables	Quality of life		p-value*	POR (95% CI)
	Not Good	Good		
Gender				
Men	26 (54.2)	22 (45.8)	0.964	0.91 (0.43-1.95)
Women	35 (56.5)	27(43.5)		
Age				
≥45 years	44 (64.7)	24 (35.3)	0.022	2.70 (1.22-5.95)
<45 years	17 (40.5)	25 (59.5)		
Education				
Low	58 (57.4)	43 (42.6)	0.163	2.70 (0.64-11.40)
High	3 (33.3)	6 (66.7)		
Married Status				
Divorced	21 (70.0)	9 (30.0)	0.096	2.33 (0.95-5.71)
Married	40 (50.0)	40 (50.0)		
Knowledge				
Low	52 (69.3)	23 (30.7)	0.000	6.53 (2.65-16.11)
High	9 (25.7)	26 (74.3)		
Income				
≤1 million	57 (61.3)	36 (38.7)	0.009	5.15 (1.56-17.01)
>1 million	4 (23.5)	13 (76.5)		
Family support				
Lack of support	45 (76.3)	14 (23.7)	0.000	7.03 (3.03-16.33)
Good support	16 (31.4)	35 (68.6)		
Attitude				
Not good	25 (73.5)	9 (26.5)	0.019	3.09(1.27-7.48)
Good	36 (47.4)	40 (52.6)		
Stigma				
Yes	42 (71.2)	17 (28.8)	0.001	4.16 (1.87-9.26)
No	19 (37.3)	32 (62.7)		
Disability				
Yes	13 (61.9)	8 (38.1)	0.677	1.39 (0.52-3.68)
No	48 (53.9)	41 (46.1)		
Duration of leprosy				
> 3 years	11(68.8)	5 (31.3)	0.376	1.94 (0.62-6.01)
≤ 3 years	50 (53.2)	44 (46.8)		

\*Based on the Chi-square test

Based on multivariate analysis, determinant factors of quality of life were stigma, knowledge, income, family support, and age, with a prevalence odds

ratio (POR) of 10.26, 8.17, 7.37, 7.31, and 4.10 successively (Table 6).

**Table 6. Significant Determinants of Quality of Life using Logistic Regression**

Variable	P-Value	Prevalence Odds Ratio	95% CI for POR	
			Lower	Upper
Stigma	0.000	10.26	3.02	34.89
Knowledge	0.002	8.17	2.23	29.97
Income	0.016	7.37	1.46	37.37
Family support	0.000	7.31	2.43	22.01
Age	0.015	4.10	1.31	12.80

**DISCUSSION**

This study was conducted in Talango which has the highest prevalence rate and new case detection of leprosy among other sub-districts in Sumenep. However, the number of disabilities due to this disease is relatively lower than in other areas in Indonesia, due to good monitoring of the treatment program<sup>16</sup>.

Leprosy is not a barrier to marriage because more than 80% of the respondents were married<sup>9, 17</sup>. Concerning gender, we found a greater prevalence of female leprosy; the same thing was found in other studies<sup>12, 18</sup>. On the broader leprosy literature, a greater prevalence is seen among men because of their more extensive social contact<sup>5, 19-21</sup>. We found more than 50% of leprosy persons had a negative stigma.

Our study revealed that leprosy disease influenced the quality of life (QoL), where more than half of the respondents had a poor quality of life (55.5%). Geetha et al. found that 17.8% of people affected by leprosy had poor QoL, using the same index<sup>17</sup>. Another study by Das et al. on 114 leprosy patients using the Dermatology life quality index (DLQI) found that 32.46% had a moderate impact, and 34.21% of patients had a severe impact on the QoL.

According to WHO, quality of life is individual perceptions about their lives in the cultural context and norms and relationship to their goals, expectations, standards, and concerns, influenced by physical, mental, psychological health, personal beliefs, and social relationships with the surrounding environment<sup>22</sup>. The social and physical health domain had the highest score of all four domains. This finding is reasonable due to the low number of disabilities and deformities among the subjects. Deformities have multiple impacts on leprosy patients because they cause functional limitations and a decreased perception of physical health. In other studies, physical domain scores were lower in deformed than in non-deformed patients<sup>2, 9</sup>. The lower score in the psychological domain was due to the unavailability of supportive social networks and psychology services that could enhance the capacity of patients to cope with the

disease. Environmental aspects had the lowest score because of the restricted transportation access to Talango, which can only be reached by boats or ferries.

The multivariate analysis showed a significant relationship between quality of life (QoL) and the following determinant factors, i.e., stigma, knowledge, income, family support, and age. This study found that stigma affected the quality of life with a POR of 10.26. Tsutsumi et al. (2007) and Rahayuningsih (2012) found that perceived stigma had the most substantial relationship with a decrease in the quality of life of leprosy patients<sup>2, 12</sup>. Stigma against leprosy people and their families negatively impacts their quality of life, even for the cured patients, because the disease has interfered with their mobility, interpersonal relationships, marriage, work, leisure time, and social activities<sup>12, 17, 21, 23</sup>. Perceived stigma portrays the patient's perception of the attitudes of others, such as fears and discrimination. They did not reveal their disease status because they feared rejection and losing their job<sup>21</sup>. In our study, most respondents did not feel discrimination at their workplace because they worked in agricultural fields or fisheries. Stigma could be caused by inadequate or incorrect knowledge about the disease<sup>17, 24</sup>. Because of the stigma and the lack of knowledge about the disease, leprosy patients sometimes take a quite long time to seek adequate and specialized treatment<sup>25</sup> until they develop a physical deformity<sup>10, 23</sup>. In a study conducted in a major leprosarium in Japan, stigma caused depression and suicide<sup>24</sup>. In a study in Tanzania, people who suffered from leprosy were shunned by their families. Their family members did not dare to touch them. A person with leprosy was considered a burden and must be removed from the family<sup>3</sup>.

Regarding knowledge of leprosy, half of the samples were still not aware of the infectious nature of leprosy, such as the cause, the symptoms, the consequences, and mode of transmission; a similar result was found in India<sup>9</sup> and Brazil<sup>21</sup>. However, most of the respondents knew about the treatment aspects of leprosy; since they were receiving treatments or had completed the treatment with multidrug therapy at the time of the interview.

Knowledge about the symptoms of leprosy, its consequences, and its mode of transmission is crucial in promoting early diagnosis and treatment, preventing further progression, and spreading of the disease.

Lack of knowledge had a bad impact on the quality of life of leprosy-affected people. Previous studies suggested that knowledge influences the attitude towards leprosy. Lack of knowledge about leprosy generally leads to a negative attitude towards individuals with leprosy<sup>23, 25, 26</sup>. Knowledge was significantly related to education and poverty. Poor financial condition is one of the major obstacles that hinder people from pursuing higher education. Low education level, in turn, contributes to a lack of health knowledge and a higher incidence of leprosy in several studies<sup>12, 15, 21, 27</sup>.

Given that Sumenep is a high leprosy endemic area, it is worrying that only half of the respondents possessed a good knowledge of leprosy. Lack of knowledge about the infectious nature of leprosy will hinder the leprosy control program. Increasing public knowledge about leprosy by disseminating information widely to the family level is really needed, as stated in Regulation of the Minister of Health of the Republic of Indonesia Number 11 of 2019 concerning Management of Leprosy<sup>28</sup>. It is also important to provide information about the early signs and symptoms of leprosy, and programs for the management of leprosy. Ministry of Health and District Health Office has to manage the strong partnership with the communities and relevant NGOs to strengthen leprosy management policies and programs<sup>28</sup>.

As seen in other countries, leprosy still haunts people from Indonesia's lower economy and education status. Most of our respondents earned less than 1 million rupiah (around 70 USD) per month, which was below the minimum standard of salary. More than half of the respondents (62.7%) did not attend/complete elementary school. This situation was also similar to a study in India in which more than 50% (52.94% - 66.9%) were illiterates. Many studies found that low socioeconomic conditions significantly impact leprosy patients<sup>12, 13, 15, 20, 29</sup>. Financial situations may influence the way an individual treats a health-related problem. A meta-analysis study highlighted the association between disadvantageous economic circumstances and the risk of contracting leprosy<sup>30</sup>.

Family support is necessary for completing the treatment process. We found in our study that family support was quite good, especially in supporting the patients to complete the treatment. Similarly, a study in Brazil also reported that almost all (98.6%) patients received support from family or a life partner<sup>21</sup>. There was a significant association

between family support and treatment compliance in leprosy patients, which was found by Fatmala<sup>29</sup>. In our study, people above 45 years old are more likely to get leprosy. Similarly, Geetha et al. also reported that the percentage of leprosy patients over 45 years was 91.4%<sup>17</sup>.

The limitation of the study was that the sample size was not big, so that some associations had less precise interval estimates as indicated by quite a wide 95% CI of POR for some determinants.

## CONCLUSIONS

We found more than 50% of leprosy-affected people in the Talango subdistrict had poor quality of life. Significant determinant factors for the quality of life of leprosy-affected people were stigma, knowledge, family support, income and age. To improve the quality of life of people affected by leprosy, it is necessary to deal with stigma through counseling, group therapy and physical and occupational rehabilitation. Health promotion activities should be directed at empowering families and the community to play an active role in changing people's behavior and modifying the social environment (especially for eliminating stigma and discrimination) and maintaining and improving general health.

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