

The Relationship of Degree of Disability and Quality of Life Among Released From Treatment People Affected by Leprosy in Surabaya, Indonesia

APW Utama¹, P Hastuti², MZA Rustam³

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Amount of disability makes leprosy an important public health problem world over. The disability in leprosy like physical defects lead to dissatisfaction in the lives of people affected by leprosy (PALs). Involvement of skin and peripheral nerves impact on disability which may influence on quality of life (QOL) among PALs. This study has been carried out to analyze the relationship between degree of disability and QOL among PALs in Surabaya. This cross-sectional study included 44 PALs living in UPTD Babat Jerawat, Surabaya, Indonesia. A self-administered questionnaire was used to study the socio-demographics of PALs, whereas the degree of disability was assessed by WHO Disability Grading for hands & feet and eyes. QOL were assessed using observation sheet and WHO-QOL, respectively. Spearman Analytic test was used to analyze the correlation between degree of disability and QOL among PALs. The degree of disability among PALs was level 1 in 27.3% and level 2 in 72.7%. 47.7% had poor quality of life whereas remaining 52.3% had a good quality of life. There was a significant relationship between degree of disability and QOL among PALs ($p=0.011$) among PALs. Interestingly, 19 people (59.4%) with the level 2 disability had a poor quality of life, however, 13 people (40.6%) with the same level 2 disability had a good quality of life. The conclusion of this research is the level of disability was found to be related to the quality of life of the RFT PALs in Babat Jerawat Benowo Surabaya. The disabilities drive in negative response in their life, which affects on their quality of life too. This means that QOL can be improved in a major section of PALs by appropriate strategies. Therefore, improving the QOL should be a priority in the existing programs, particularly in PALs with disabilities.

Key words : Patients Affected by Leprosy, Disability, Quality of Life, Indonesia

Introduction

Leprosy is possibly a manifestation of poverty because in reality most of People Affected by Leprosy (PALs) come from the economically lower-level community. Leprosy, if not treated carefully, may cause a physical defect, and this

situation may become a barrier for leprosy sufferers to meet their socio-economic needs (Widoyono 2011). The amount of disability makes leprosy an important public health problem world over. This disability in Leprosy is also a cause for stigma and discrimination (Sharma and Saxena

¹ Andita Putri Winda Utama

² Puji Hastuti

³ Muh. Zul Azhri Rustam

Stikes Hang Tuah Surabaya, East Java, Indonesia

Correspondence : Puji Hastuti, **Email :** pujihastutisby@gmail.com

2019). The psychological condition of the sufferers may also be seriously affected because of the negative stigma from the common people that leprosy is a fearsome disease; even some consider it as a curse. This is because the impact caused by the disease is quite severe, i.e., the deformity/defect in parts of the body (Rismayanti et al 2017). A research conducted by Making et al (2008) about the description of the quality of life of the leprosy people in Lembata Regency, East Nusa Tenggara Province, showed that the physical limitations experienced by the PALs could reduce their ability to work and do various activities. Furthermore, the stigma of physical defect(s) also made them feel discouraged and resulted in lack of confidence which eventually made them feel dissatisfied with their life. PALs preferred to hide and avoid their social life. Leprosy, if not treated quickly and precisely, may cause physical, social and psychological changes in the form of physical defects/deformities and limitations which then decline the lepers' quality of life. Besides, the types of works that require excessive physical activity may result in a more severe physical defect. The result of a preliminary study conducted on February 1, 2018, through an observation and interview with one of PALs and the manager of the leprosy rehabilitation center in Babat Jerawat Benowo Surabaya, found out that some of them had hand deformities. The manager of the rehabilitation center also said that on average >90%, PALs had been declared RFT (Released From Treatment).

The incidence of leprosy in the world in 2016 based on WHO data has increased, namely from 211,973 in 2015 to 214,783 in 2016. As many as 14 countries reported >1000 new cases each year. Southeast Asia is the region with the highest incidence of leprosy which is 161,263 cases in 2016. Indonesia is a country which is third highest contributor to leprosy incidence in the world,

namely as many as 16,286 cases, after Brazil (25,218 cases) & India (145,485 cases). East Java is the province with the highest incidence of leprosy on Java, which is 3,373 the number 2 cases and cases of leprosy defect are number 2 highest, as many as 293 cases in last year 2017 (Tami 2019). The prevalence of leprosy in Surabaya city in 2015 was 0.97% per 10,000 people with 9 people (9.28%) experiencing the level 2 of disability (Dinas Kesehatan Provinsi Jawa Timur 2016). In East Java, the success of treatment (RFT) in 2015 exceeded the target (>90%). Cumulatively starting from the beginning of the program until the end of December 2015, PALs who could complete the MDT treatment were 136,544 people. The RFT rate at the provincial level reached 91.1%, while the RFT rate in 22 districts/cities reached >90%. Based on several studies, PALs with disability were mostly farmers (35%). The number of PALs in Babat Jerawat Benowo Surabaya was around 55 people who lived together with their healthy families. PALs mostly worked as traders and some were gardeners.

Most of PALs got physical disability before getting medical treatment due to the lack of awareness and knowledge from the clients, families, and even the surrounding community about the importance of early detection of leprosy. The image of leprosy disabilities often makes the sufferers experience changes in personality, tendency to hide, and reduce their social activities. This may obstruct the process of treatment, healing and increase the risk of disability which may affect the PALs' quality of life. Physical defects may affect PALs' behavior in the form of withdrawal from their social environment. Besides, the disabilities may make the PALs lose their jobs and often make them choose to vagrancy and beg. PALs in Babat Jerawat Benowo Surabaya commonly worked as traders, pedicab drivers and scavengers because those were the

kinds of jobs they could do. It shows that the physical defect experienced by leprosy people may not only cause them to lose their job but also affect their self-confidence and social life. Even it can also make them experience mental disorders because they cannot accept their physical condition.

Researches on the quality of life of PALs showed that some PALs experienced a decreased quality of life both socially and psychologically (Making et al 2008). There should be an effort to make the sufferers especially those experiencing disability optimistic in living their life by optimizing the other body parts that are still normal. Besides, one of the therapies that can be done to improve their quality of life is forming a Self Help Group (SHG) (Widianti et al 2018). The purpose is to provide support to the fellow members and make the process of problem solving better. Here, they can share feelings and experiences, learn about the illness, provide opportunities for the lepers to talk about their problems and choose what to do, hear one another, help the fellow members to share ideas and information as well as provide support, and increase caring among the fellow members so that they would achieve a feeling of security and prosperity and understand that they are not alone. Increased support and motivation from the family members and the surrounding communities are also badly needed by the sufferers to have a better quality of life. The objective of study is to analyze the relationship between the level of disability and the quality of life of the PALs who has RFL in Babat Jerawat, Surabaya.

Materials and Methods

This study used an observational analytic method with a cross-sectional approach and was conducted on 26th May 2018. The respondents in this

research were PALs living in Babat Jerawat, Surabaya, with a total number of 55 people, The sampling technique applied was the Non Probability Sampling with the Purposive Sampling approach because the researcher determined the sampling by specifying the characteristics that fit the purpose of the research. The sample size was calculated by the formula obtained by 44 participants, who were meeting the inclusion criteria were included in the study :

Inclusion criteria :

1. PALs with disability
2. PALs with productive age (15 - 64 years old)

Exclusion criteria :

1. PALs who are pregnant.

The measuring instruments utilized were the observation sheets to assess the level of disability experienced by the PALs with WHO Disability Grading was done for 1) Hands and feet and 2) Eyes as per criteria given below (Brandsma and van Brakel 2003, Alberts et al 2011).

Hands and feet	
Grade 0	No anesthesia, no visible deformity or damage.
Grade 1	Anesthesia present, but no visible deformity or damage.
Grade 2	Visible deformity or damage present.
Eyes	
Grade 0	No eye problem due to leprosy; no evidence of visual loss.
Grade 1	Eye problems due to leprosy present, but vision not severely affected as a result (vision: 6/60 or better; can count fingers at 6 meters).
Grade 2	Severe visual impairment (vision worse than 6/60; inability to count fingers at 6 meters); also includes lagophthalmos, iridocyclitis and corneal opacities.

Assessment of disability experienced by people with leprosy can use a score called Eye Hand Foot (EHF), despite, the EHF score is better used at programme level than individual patient level (Ebenso & Ebenso 2007). How to assess the EHF score is by adding up the number of defects in the assessed body parts, namely the eyes, hands and feet.

The WHOQol-BREF questionnaire sheets was used to assess the quality of life of the PALs. The

questionnaire totaled 26 questions consisting of 7 questions for the physical domain, 6 questions for the psychological domain, 3 questions for the social domain and 8 questions for the psychological domain. The four domain scores represent an individual's perception of the quality of life in each particular domain. The domain score scales in a positive direction (higher scores indicate higher quality of life). The value range is 0-100 (WHO 2004).

Table 1 : Demographic Variable of PALs and Quality of Life (n=44)

Demographic Variable (Means)	Quality of Life	
	Poor	Good
Means Age (53 years)		
Gender		
Male	17 (81.0%)	14 (60.9%)
Female	4 (19.0%)	9 (39.1%)
Marital Status		
Married	19 (90.5%)	21 (91.3%)
Single/Not Yet Married	2 (9.5%)	2 (8.7%)
Education Level		
No School	4 (19.0%)	3 (13.0%)
Elementary	15 (71.4%)	18 (78.3%)
Junior	1 (4.8%)	2 (8.7%)
Senior	1 (4.8%)	0 (0%)
Working		
Not Working	7 (33.3%)	0 (0%)
Entrepreneur	2 (9.5%)	9 (39.1%)
Fisherman	2 (9.5%)	1 (4.3%)
Housewife	2 (9.5%)	3 (13.0%)
Etc	8 (38.1%)	10 (43.5%)
Frequency of Leprosy Treatment		
Regularly	20 (95.2%)	21 (91.3%)
Not Regularly	1 (4.8%)	2 (1.6%)
Type Leprosy		
Multibacillary (MB)	14 (66.7%)	7 (30.4%)
Paucibacillary (PB)	7 (33.3%)	16 (69.6%)

Informed consent in writing was obtained from all the study participants prior to interview. Observations and interviews with respondents were conducted to determine the level of disability of the respondents and write them on the observation sheet. Researchers distributed Quality of Life questionnaires and explained according to the instructions to measure the quality of life of leprosy respondents. The completeness of all results was checked to make sure the information has been filled according to instructions. Data was analyzed using Microsoft Excel 2013. The categorical variables were presented as frequency and percentages.

Results

Demographic data of respondents including the type of leprosy are shown in Table 1.

The number of 44 participants from the PALs RFT, consisting of 31 (70.45%) of participants were male and 13 (29.55%) female. Mean age of respondents was 53 years old. Marital Status of participants were 40 (90.9%) married and 4 (9.1%) single/not yet married. Education level were highest at elementary level of 33 people (75%). None of the respondents' jobs work in

the government, more in the private sector like pedicab drivers 18 (40.9%), and traders and fisher 14 (31.8%), and 12 (27.27%) no working. Participants with routine of frequency of leprosy treatment are 41 (93.18%) and not routine are 3 (6.82%). Type of leprosy included 21 (47.7%) Multibacillary (MB) and 23 (52.3%) Paucibacillary (PB) as per WHO classification (WHO 2012).

Table 2 shows that out of 44 respondents, no respondents had 0 defect, 12 respondents (27.3%) got level 1 defect and 32 respondents (72.7%) experienced level 2 defect. The results of the research concerning the level of disability experienced by the respondents showed that most of them got the level 2 defect, amounting to 32 people (72.7%) out of 44 respondents.

As shown in Table 3, out of 44 respondents, 21 people (47.7%) had a poor quality of life and 23 people (52.3%) had a good quality of life.

Analysis of correlation between the level defect and the quality of life shows that out of 44 respondents, 19 people (59.4%) with the level 2 disability had a poor quality of life, however, 13 people (40.6%) with the level 2 disability had

Table 2 : Level of Disability in Persons Affected by Leprosy (n = 44)

No.	Defect Level	Frequency (f)	Percentage (%)
1	Level 0 defect	0	0
2	Level 1 defect	12	27.3
3	Level 2 defect	32	72.7
	Total	44	100

Table 3 : Quality of Life of the Respondents (n = 44)

No.	Quality of Life	Frequency (f)	Percentage (%)
1	Poor Quality of Life	21	47.7
2	Good Quality of Life	23	52.3
	Total	44	100

Table 4 : Correlation between the level of defect and the quality of life of the respondents (n=44).

No.	Level of disability	Quality of life		Total
		Poor Quality of Life	Good Quality of Life	
1	Level 0 disability	0	0	0
2	Level 1 disability	2 (16.7%)	10 (83.3%)	12 (100%)
3	Level 2 disability	19 (59.4%)	13 (40.6%)	32 (100%)
	Total	21 (47.7%)	23 (52.3%)	44 (100%)

Spearman's Test rho 0.011 ($\alpha = 0.05$), Correlation coefficient 0.381

a good quality of life. Besides, 2 people (16.7%) with the level 1 disability had a poor quality of life and 10 people (83.3%) with the level 1 disability had a good quality of life (Table 4). The results of the Spearman Rho test between the level of disability and the quality of life of the respondents were $\rho = 0.011$ with a significant value of $\alpha = 0.05$ as a comparison. Statistically, $\rho = 0.011 < 0.05$ showed that there was a significant relationship between the level of disability and the quality of life of the respondents.

Discussion

The result showed that out of 44 respondents, as many as 23 people (52.3%) had a good quality of life. The result of crosstabs between the quality of life and the age of the PALs revealed that 17 respondents (70.8%) aged between 46-60 years old had a good quality of life. This may be because the people who enter their pre-elderly age group are commonly more expressive of their welfare. In the elderly, people have passed the time to make changes in their life so that they tend to evaluate their life more positively than in their youth. Moreover, their thoughts are more mature so that they tend to think positively which may encourage themselves. Data from the cross-tabulation showed that the married respondents had a good quality of life, amounting to 21 people

(52.5%). The result is in line with a research conducted by Making et al (2008) who observed that the support from a spouse or family is very much needed by the sufferers because leprosy commonly changes a person's physical appearance. Therefore, a person affected with leprosy will tend to look for someone he considers trustworthy who can revive their confidence and provide positive support to him. A support from a spouse and family can provide comfort and provide peace to the PALs who are commonly feeling depressed due to their illness.

The data also showed that 21 people (47.7%) out of 44 respondents had a poor quality of life. The result of crosstabulation indicated that the poor quality of life was related to gender. More males, 17 people (54.8%), had the poor quality of life. This is because for a leprosy man it is a threat to his role as the head of the family. The leprosy may decrease his productive capacity and decrease his bodily function as well as decrease his sexual potential. Besides, this can also make a PAL man lose his job and reduce his confidence to work. The relationship between works and health problems has long been known. According to Azrul Azwar (in Rismayanti et al 2017), every job has its own risk. The kind of disease suffered may be in line with the kind of job and the socio-economic status of someone.

The result of the second cross-tabulation showed that the duration of suffering from leprosy significantly correlated with the level 2 disability. Out of 32 respondents with the level 2 defect, 13 people (40.6%) suffered from leprosy for around 36-53 years. An interview with them showed that they were first affected by leprosy when they were in their childhood and some were in their teenage. But due to lack of knowledge and information about the early treatment of leprosy and lack of maintaining personal hygiene and attention to their health, they were detected to have leprosy after years of leprosy infection and they got the level 2 disability (Yuniarasari 2014). Leprosy, if not treated immediately and well cared, may cause severe defect or deformity. This was also experienced by the respondents. This result is the same as that of the research conducted by Witama et al (2014) about the characteristics of leprosy patients with the level 2 disability in the Leprosy Hospital of Alverno Singkawang. The result of this research showed that the level 2 disability at the time of diagnosis could be the risk factor of the worsening of the disability or the emergence of new defect during or after treatment and after the patient was declared RFT.

The result of the research also revealed that there were 12 people (27.3%) out of 44 respondents who got the level 1 disability. The defect is characterized by the impaired sensory functions such as numbness and reduced eye vision. The result of observation and interview showed that most of the respondents who had the level 1 disability experienced numbness in their hands (32 people) and in their feet (31 people), whereas only 6 people experienced reduced eye vision (visual acuity). Level 1 disability, if not treated quickly, will develop into level 2 disability. For this reason, there should be counseling of self-care

methods to the leprosy people so that any severe deformity can be prevented and minimized.

The result of crosstabulation revealed that all respondents experienced a disability either the level 1 or level 2 disability. This was because most of the respondents only had got primary education (elementary school) so that their knowledge of the disease was very limited. They often thought it was a trivial disease and not dangerous to their health and tended to ignore the information provided by the health workers. According to Susanto cited in Sari et al (2015) lower level of education was one of the factors which made PALs have late medical treatment for their leprosy. Low education results in a lack of knowledge about leprosy. Moreover, the families of the lepers commonly do not have an adequate understanding of the bad consequences of leprosy as well. As a result, they generally got medical treatment after they had experienced a deformity. The result of this research is the same as the research conducted by Putra et al (2009). He explained that the main factor causing a defect in leprosy patients was the delay in having medical treatment. Most of PALs were less aware of their health and paid less attention to the skin disorders they suffered. Abnormalities that occur in PALs are generally only in the form of white or red patches that develop slowly and are commonly ignored by PALs. The people usually take medication if the disorder has disturbed their activities, e.g., when the ulcers have occurred on feet, stiffness in the fingers and increased body temperature as the result of leprosy reactions.

After conducting the Spearman correlation test (Table 4) between the levels of defect and the quality of life of the respondents, it was obtained that $\rho=0.011$ with a significant value of $\rho=0.05$ as a comparison. Statistically $\rho=0.011 < \rho=0.05$ indicated that there was a relationship between the levels of defect and the quality of life of the

respondents. Correlation coefficient obtained 0.381 which means that there was a significant correlation between the levels of defect and the quality of life. In other words, the higher the level of defect experienced, the worse the quality of life of the leprosy people. This research found out that the respondents with level 2 defect whose quality of life was poor outnumbered those who had a good quality of life. The result of this research is the same as that of the research conducted by Hane (2017) cited in Muna & Fibrina (2019) showing that the higher the level of defect, the lower the quality of life of the leprosy people.

The result of crosstabulation revealed that among the respondents with level 1 defect, 2 people (16.7%) had a poor quality of life and 10 people (83.3%) had a good quality of life. Whereas among the respondents with level 2 defect, 19 people (59.4%) had a poor quality of life and 13 people (40.6%) had a good quality of life. Based on these results it can be concluded that many people with leprosy still had a poor quality of life due to the physical defect they had. From the interview, it was known that many of the lepers lost their jobs and confidence to work. Besides, the physical defect may make the other people isolate them, including their families and the closest ones, which may worsen their quality of life. At the level 1 defect, there is no clear physical defect, only a sensory disturbance and reduced eye visus. However, at the level 2 defect, the physical defect is visible because the leprosy sufferers experience physical changes in their body parts. Therefore, the level 2 defect commonly worsens the quality of life of the leprosy people. However, out of 44 respondents, as many as 2 sufferers with the level 1 defect had a poor quality of life. It was because the respondents did not get any support from the others, including their families. They said that they lived alone and were unmarried though they had been

old enough; consequently, they felt lonely and had no enthusiasm to live their lives.

The result of this research showed that the types of leprosy significantly correlated with the level 2 disability. As many as 12 people (52.2%) were identified to have the paucibacillary (PB) leprosy and 20 people (95.2%) had multi bacillary (MB) leprosy. According to WHO, the type of leprosy is divided into two: paucibacillary (PB) and multibacillary (MB) which can be distinguished from the lesions on the skin and nerve damage (WHO 2012). PB leprosy, often called dry leprosy and not infectious, is characterized by the presence of whitish spots like phlegm commonly accompanied by numbness, dry and rough patches, uncovered with hair, and the patches spread on the skin at 1 to 5 places. This type of leprosy only attacks one branch of the peripheral nerve. MB leprosy, often known as wet leprosy and more infectious, is characterized by the reddish-white patches spreading throughout the skin of the body, with swelling in the spots, numbness and muscle weakness, and the patches spread on the skin at more than 5 places. The leprosy of this type also causes damage to the peripheral nerves. The result of interview and observation indicated that the defects experienced by the respondents were mostly due to MB leprosy. The level 2 defect experienced by MB leprosy respondents was due to the nature of MB leprosy which can spread bacilli faster than PB type. Lepra bacilli may quickly spread to all parts of the body – especially the skin and peripheral nerves – because the cellular immune system of the MB sufferers is weak. As a result, peripheral nerve damage followed by deformity/defect may occur. The respondents said that they experienced the characteristics of MB leprosy. However, due to lack of information, they ignored the signs and symptoms because they thought they were just ordinary skin diseases. Another respondent

said that firstly, he thought that the spots on his skin were merely phlegms or ringworms which could disappear in a short time. But then they gradually developed into lesions and muscle weakness in their hands and feet. When the respondents started to have deformity they went to the clinic and found out that that they had MB leprosy. This result is in line with a research conducted by Umayá et al (2016) in which authors explained that the main factors of deformity in people with MB leprosy were the occurrence of nerve thickening (≥ 3 nerves at diagnosis) and delay of treatment (> 36 months). There was no data that showed a history of nerve thickening at the first diagnosis. However, it was identified that on average, the respondents started to have MDT after 3.2 years after suffering from leprosy.

There are three stages of the pathogenesis of disability caused by leprosy: First, nerve abnormalities or disorders which are characterized by nerve thickening and pain with no disturbance in motion function, but with a disturbance in the sensory system. Second, nerve damage characterized by incomplete paralysis or initial paralysis in the eyelid, finger, and foot muscles. At this stage, the recovery of muscle strength can still occur. If it continues, injuries to the eyes, hands and feet and stiffness of joints may occur. Third, it is nerve destruction or persistent paralysis (Susanto 2006). The characteristics of the level 2 defect can be identified by the occurrence of lagophthalmos (eyelids cannot cover the eyeball, hand and feet deformity, shortening/mutilation, and the presence of ulcers). The result of observation showed that 6 people had eye visual acuity problem, 35 people experienced lagophthalmos, 12 people experienced loss of touch sense on hands, 32 people had ulcers on hands, 14 people experienced hand deformity and 16 people had hand shortening/mutilation. Besides, 13 people got loss of touch

sense on feet, 15 people had feet deformity, 26 people had ulcers on their feet, and 17 people had feet shortening/mutilation. It can be concluded that in terms of the level of disability, most respondents experienced the level 2 disabilities.

The poor quality of life experienced by the PALs may be as a result of common people's belief that leprosy is a curse that can be very contagious. Therefore, the leprosy sufferers are often isolated in a group and even isolated from their social life. The quality of life is influenced by several aspects including physical health, psychology, and social relations with the surrounding environment. The quality of life is an indicator of not only how well an individual functions in his daily life but also how an individual perceives his health status which may affect his attitude toward life and his quality of life (Bello & Bello 2013 cited in Roifah 2017).

This research used the adaptation theory from Sister Calista Roy. This theoretical model focused on the concept of adaptation in humans. Most of the respondents of the research experienced physical defect making them difficult to adapt to their environment. The defects they experienced made them difficult to adapt to their current physical condition and appearance. Besides, they tended to choose to retreat themselves from the community and only wanted to get along with their fellow people affected by leprosy and their own families. This research found out that there were more males who suffered from leprosy than the females. This caused malfunctioning of their main roles of men as the backbone of the family and the head of the family. Some of them were left by their wives because they were deemed unable to become the head of the family who could meet the family's needs. The defects they experienced made them give negative responses which may have an impact on their quality of life.

PALs should better understand how to care for themselves so that the defects/deformities that occur will not get worse and routinely check their condition at the health centers. PALs should be able to think positively to increase their confidence and get rid of negative thoughts related to the stigma given by the community. PALs can also form an association that can be used as a forum to exchange information and experiences related to leprosy and provide support among the PALs. The people should provide support to PALs. By doing so, they would not feel isolated and ostracized so that the quality of their life would be better.

Conclusion

The conclusion of this research is the level of disability was found to be related to the quality of life of the RFT PALs in Babat Jerawat Benowo Surabaya. The PALs' disabilities drive in negative response in their life, which affects on their quality of life too. However, these results can not be generalized to the other colonies, the variables that have been discussed can be considered to improve the quality of life by proper interventions and right strategies. Further research should be continued on these issues.

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