

## Disability in Leprosy: Daily Activities and Social Participation in Indonesia

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**KEYWORDS** Deformity. Lifelong Disability. Physical Activity. Neglected Tropical Diseases Participation. Social Participation

**ABSTRACT** Leprosy is one of the eight neglected diseases. The purpose of this study was to explain the effect of leprosy disability on daily physical activity, and social participation of leprosy clients in Malang and Sumberglagah Hospital, Mojokerto. The study used a cross sectional design. Respondents amounted to 100 people who have met the inclusion and exclusion criteria with purposive sampling technique. Data analysis used Rho Spearman test to measure activity and participation variables. Spearman Rho test for leprosy on activity limitations showed  $p = 0.000$ . Spearman Rho test of leprosy on limited participation showed  $p = 0.000$ . Activities are limited, and participation is mostly due to the degree 2 disability experienced. The second most common disability conditions are curly fingers, deformities, and foot ulcers. Preventive efforts of the health office, especially the health centre, should provide health promotion media through the provision of foot exercises.

### INTRODUCTION

Leprosy is one of eight neglected tropical diseases (NTD) that still exist in Indonesia (Kementrian Kesehatan 2015; Arif 2020b). Leprosy is caused by *Mycobacterium leprae*, which attacks the skin and peripheral nerves and several others tissues and then causes lifelong disability (Brakel et al. 2012; Roy et al. 2020). The most important burden of leprosy is disability in the eyes, hands and feet (Wewengkang et al. 2016; Arif et al. 2017). The International Classification of Function Disability and Health (ICF) describes disability as a term used to cover three aspects including structure and function damage, activity limitation, and participation problem (Aditama 2012; Arif 2020a).

Leprosy disability often results from delays in case finding (Susanto et al. 2017). Delay in the discovery of leprosy cases will result in sensory, motor and autonomic nerve damage (Slim et al. 2010). Thickening of the peripheral nerves accompanied by impaired nerve function is a result of chronic peripheral nerve inflammation (Aditama 2012). This nerve function disorder is in the form of impaired sensory function (anaesthesia), impaired motor function (paresis, paralysis), and impaired autonomic function (dry and cracked skin) (Slim et al. 2010; Aditama 2012; Brakel et al. 2012).

The incidence of disability in leprosy is mostly found in the hands and feet area, which is almost eighty-three percent of who experience disability in the hands and feet (Slim et al. 2010). Defects in leprosy can occur before MDT treatment, during MDT treatment or after completion of treatment (Wewengkang et al. 2016). The degree of disability of leprosy according to the World Health Organisation can be divided into three degrees, namely disability degrees 0, 1 and 2 (Aditama 2012).

Leprosy disability degree 0 is a condition where there is no eye abnormality due to leprosy, and there is no deformity of the palms and feet caused by leprosy (Aditama 2012). Leprosy grade 1 disability is a condition where there is eye damage (anaesthesia in the cornea, but visual impairment is not severe, that is, more than 6/60), on the palm of the hand or foot there is anaesthesia or muscle weakness (no defects or damage seen directly by the eye) (Aditama 2012). Grade 2 leprosy disability is a condition in which there is eye damage (lagostalmus, iridocyclitis, corneal opacification and severe visual impairment of more than 6/60), and on the palms or feet there are visible defects or damage due to leprosy (for example, ulcers, clawing fingers, drop foot) (Aditama 2012).

The Ministry of Health's 2017 report on Indonesia's health profile showed that in 2017 the number of new leprosy cases was 2007 (Budijanto 2018). This number is the highest among all provinces in Indonesia. The number of level 1 disabilities was

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208 patients (10.41%), and the number of level 2 disabilities was 158 people (7.91%) against a target of less than five percent (Budijanto 2018).

Patients suffering from leprosy mostly experienced physical damage and disability after release from treatment (RFT) (Brakel et al. 2012). Disabled leprosy clients will also experience activities and participation limitations, as well as anticipation of stigma (Slim et al. 2010; Brakel et al. 2012). The limitation of daily activities carried out by leprosy clients based on WHODAS-II is the most limited in household or work activities and 'traveling around' (Slim et al. 2010). Participation problems occur when patients lose autonomy outside the home, and lose family roles due to limited activity and interference with the hands (Slim et al. 2010; Brakel et al. 2012; Silva et al. 2014; Ayode et al. 2016).

The level of disability is very influential on every activity of leprosy patients (Babu et al. 2015). In addition, when disabilities occur that are seen by others, the participation of leprosy patients in the community will decrease due to the fear experienced by patients and negative stigma in the community on leprosy. On this basis the researcher intends to look for the effect of the disability on the activities and participation of leprosy clients.

### Objective

The purpose was to explain the effect of leprosy disability on daily physical activity, and social participation of leprosy.

### MATERIAL AND METHODS

The design in this study used cross sectional design. The study population used an affordable population (Accessible Population), namely leprosy patients in the area of Malang district health centre and Sumberglagah Leprosy Hospital Mojokerto. The research sample used was 100 people. Respondents were chosen using purposive sampling techniques that fulfil the inclusion and exclusion criteria. Inclusion criteria consisted of multi-bacillary leprosy sufferers, and did not experience leprosy reaction. Exclusion criteria consisted of patients not in critical condition. The independent variable of this study is disability. The dependent variable of this study is daily activities, and social participation.

Measurement of leprosy disability was through a questionnaire with a WHO degree of disability classification approach. Measurement of activity limitations uses a questionnaire sheet using a modified Screening of Activity Limitation and Safety Awareness (SALSA) scale. Measurement of the limitations of activities was through a questionnaire using a modification of participation scale.

The collected data was analysed using univariate frequency test, crosstab test, and bivariate test using spearman rho. The significant value used in test was 0.05. Ethical clearance in this study used two institutions, namely the Ethics Commission of the Health Polytechnic of Ministry of Health Malang, and the Ethics Commission of Sumberglagah Leprosy Hospital Mojokerto. The results of ethical clearance in this study from the two institutions are qualified ethical clearance.

### RESULTS

A total of 100 cases were registered during the study period. Table 1 describes the characteristics of the majority of respondent family types is main family as many as 80 people (80.0%). The age characteristics of the majority of respondents aged 46-55 years were 33 people (46%). Educational characteristics of the majority of respondents having an elementary school education were 49 people (49.0%). The characteristics of the gender of the majority of respondents were male as many as 64 people (64.0%). Occupation of the majority of respondents was working as housewives or not working at 46 people (46.0%). Characteristics of the majority of leprosy respondents were multi-leprosy type as many as 82 people (82.0%). The characteristics of the length of suffering from leprosy, some respondents have been more than 20 years as many as 31 people (31.0%). Characteristics of the treatment period of the majority of respondents had completed MDT treatment as many as 88 people (88.0%).

Table 2 illustrates the results of the analysis test between the variables of the degree of leprosy disability and the activity variable using the spearman's rho test, showing a p-value of 0.000, which means that there is an influence of the level of leprosy disability to the limitations of leprosy client activities.

Table 3 illustrates the results of the analysis test between the variables of the degree of leprosy

**Table 1: Characteristics of respondents by type of family, age, education, gender, occupation, type of leprosy, leprosy period, and treatment**

<i>Characteristics</i>	<i>Number of respondents</i>	<i>Percentage (%)</i>
<i>Type of Family</i>		
Main family	80	80.0
Extended family	20	20.0
Total	100	100.0
<i>Age</i>		
17-25 years old	3	3.0
26-35 years old	19	19.0
36-45 years old	21	21.0
46-55 years old	33	33.0
<55 years old	24	24.0
Total	100	100.0
<i>Education</i>		
No school	21	21.0
Elementary school	49	49.0
Junior high school	23	23.0
Senior high school	6	6.0
College	1	1.0
Total	100	100.0
<i>Gender</i>		
Male	64	64.0
Female	36	36.0
Total	100	100.0
<i>Occupation</i>		
Doesn't work / Housewife	46	46.0
Farmer	26	26.0
Entrepreneur	20	20.0
Etc.	8	8.0
Total	100	100.0
<i>Type of Leprosy</i>		
Pausibasiler	18	18.0
Multibasiler	82	82.0
Total	100	100.0
<i>Leprosy Period</i>		
< 2 years	19	19.0
2 - 5 years	8	8.0
6 - 10 years	28	28.0
11 - 20 years	14	14.0
> 20 years	31	31.0
Total	100	100.0
<i>Treatment</i>		
MDT process	12	12.0
MDT completed	88	88.0
Total	100	100.0

disability and the participation variable using the Spearman's Rho test, showing a p-value of 0.000, which means that there is an influence of the level of leprosy disability to the limitations of leprosy client participation.

## DISCUSSION

Table 2 shows the majority of leprosy clients who are in a 0 degree disability condition have no limitations in carrying out activities. Leprosy clients who experience leprosy disability in the first degree mostly experience mild category activity limitations. Leprosy clients who suffer from leprosy disability of degree 2, most of them experience limitations in doing mild category activities. In addition, there were 4 respondents (8.9%) who experienced very heavy category activity limitations due to respondents having leprosy disability degree 2.

Table 3 shows the majority of respondents who are in a condition of 0 degree disability have no limitations in social participation. Leprosy clients who experience leprosy disability first degree mostly do not experience limitations in social participation. Leprosy clients who experience leprosy disability degree 2, most of them experience limitations in carrying out social participation with heavy categories. In addition, there were respondents who experienced limited social participation in the very heavy category of 1 person (2.2%) due to respondents experiencing 2<sup>nd</sup> degree leprosy disability.

Table 2 shows the results of the spearman rho test with the p-value of 0.000, which means that there is an influence of the degree of leprosy disability to the activities of leprosy clients. Table 3 shows the results of the spearman rho test showing a p-value of 0.000, which means that there is an influence of the level of leprosy disability to participation in leprosy clients.

**Table 2: Spearman Rho test and leprosy cross tabulation of leprosy disability in terms of activity limitations**

<i>Degree of disability</i>	<i>No. activity limitations</i>		<i>Mild activity limitations</i>		<i>Moderate activity limitations</i>		<i>Heavy activity limitations</i>		<i>Very heavy activity limitations</i>		<i>Total</i>	
	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>
0	7	87.5	1	12.5	0	.0	0	.0	0	.0	8	100.0
1	21	44.7	22	46.8	3	6.4	1	2.1	0	.0	47	100.0
2	0	.0	18	40.0	17	37.8	6	13.3	4	8.9	45	100.0

Spearman's Rho Test Result = 0.000

**Table 3: Spearman Rho test and leprosy cross tabulation of leprosy disability against participation limitations**

Degree of disability	No. participation limitationl		Mild participation limitations		Moderate participation limitations		Heavy participation limitations		Very heavy participation limitations		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
0	5	62.5	0	.0	0	.0	3	37.5	0	.0	8	100.0
1	31	66.0	1	2.1	7	14.9	8	17.0	0	.0	47	100.0
2	4	8.9	1	2.2	15	33.3	24	53.3	1	2.2	45	100.0

Spearman's Rho Test Result = 0.000

Leprosy is a contagious, chronic disease, and is caused by leprosy (*Mycobacterium leprae*), which is obligate intracellular (Sjamsoe 2003; Arif et al. 2017). Leprosy is a chronic disease that weakens one's physical abilities. Earlier diagnosis and early treatment will reduce the burden of disease, especially for cases with disabilities (Roy et al. 2020). Peripheral nerves are the first affinity, then the skin and upper respiratory tract mucosa, then the other organs except the central nervous system (Aditama 2012; Limaye et al. 2017). Most infected people can be asymptomatic, but in a small proportion show symptoms and have a tendency to become deformed especially in the hands and feet (Sjamsoe 2003; Slim et al. 2010; Brakel et al. 2012).

*Mycobacterium leprae* will first affect the nerves through infiltration into the peripheral nerves, which triggers destructive and intense intra-nerve edema and destruction of cells and Schwann axons, resulting in various deformities (Yang et al. 2013; Mankar et al. 2020). Leprosy patients often develop numbness in the eyes, hands and feet. Structural and functional damage in leprosy is pathological, physiological, or anatomical (for example, claw hand, ulcer, drop foot) (Aditama 2012). With the eyes, they often cannot close tightly (lagofthalmus), and become numb and dry (Aditama 2012). In the hand there will be a numb hand on the palm of the hand, dry skin, bent fingers, even amputated fingers (Aditama 2012; Lamak et al. 2014). Foot numbness often occurs in the soles of the feet, simper feet, there are wounds on the feet, thick, dry skin of the feet (Sjamsoe 2003; Aditama 2012; Lamak et al. 2014).

According to the International Classification of Function Disability and Health (ICFm) (Yang et al. 2013), disability is a term used to cover 3 as-

pects namely impairment, activity limitation, and participation problems (Velema 2010; Aditama 2012; Yusuf et al. 2020). Impairment is damage to structures and functions that are pathological, physiological, or anatomical (for example, claw hand, ulcer, drop foot) (Aditama 2012; Brakel et al. 2012).

The most common signs of leprosy are those associated with sensory fibres, including the most pain and numbness suffered (Rohmi et al. 2020). Symptomatic patients with a more severe stage of sensory damage are a higher level of disability in the lower limbs and motor damage. Health professionals must be aware of patients with these symptoms and pay more attention during evaluations to better prevent or manage disability (Do Nascimento et al. 2018).

Activity limitations are those with in carrying out activities within the limits of normal life for humans (Velema 2010; Aditama 2012). The limitation of activities is very closely related to the level of leprosy disability suffered (Velema 2010). Participation problem is a setback to someone who prevents the completion of normal tasks in their role in the community (Sumaryadi 2010; Aditama 2012; Aditya et al. 2020).

The International Classification of Function Disability and Health (ICF) explains the limitations of activities defined as conditions of difficulty for individuals to start or do activities (Velema 2010). The existence of physical disorders in leprosy patients plus old age gives the impact of limitations in self-care and loss of freedom of daily activities of lepers (Silva et al. 2014). Damage to daily activities is accelerated if leprosy clients experience ulcers or wounds on the feet, and weakness in the fingers and toes (Brakel et al. 2012; Silva et al. 2014).

The prevalence of leprosy is very high, and the damage is mostly in the hands and feet (Silva

et al. 2014; Witama 2014). The severity of leprosy disability has a significant correlation with limited activity (Slim et al. 2010).

The ability to explore, prepare food, and do the daily activities of leprosy patients around the house depends on the ability to use upper and lower limbs (Matuli et al. 2013). Members who are not free because of disability will interfere with leprosy patients in completing daily activities and affect participation and attitudes to travel and do social interaction (Arif et al. 2017; Moura et al. 2018).

The issue of participation is also related to the severity of leprosy disability (Slim et al. 2010; Silva et al. 2014). The majority of causes of limited activity are the level of severity of leprosy disability, education level, and stigma (Brakel et al. 2012).

Participation itself is defined as involvement in life situations (Sumaryadi 2010). Life situations refer to one's interactions and participation in broader aspects and areas of normal life or community life such as the social, economic, civil, interpersonal, and educational domains of daily life, most of which concern everyone, regardless of health, age, their gender or caste. Problems experienced in participating in daily life are referred to as limitations of participation (Brakel et al. 2012; Arif 2020b). The severity of leprosy disability has a significant correlation with limited participation (Slim et al. 2010). The results of participation problems show that around thirteen to thirty-two percent are mostly problematic in the domain of autonomy outside the home and the role of the family (Slim et al. 2010; Arif et al. 2017).

One of the impacts of leprosy is the limitation of daily activities. In the results of this study it appears that the degree of disability in respondents has a significant influence on the activities of leprosy clients. Activity limitations are defined as the inability to start or carry out activities. The limitation of activities in this study was due to a degree of disability experienced by respondents. The second degree of disability that occurs in most respondents is kiting fingers, deformity, and ulcers or sores.

The majority of respondents who experienced second degree had difficulty in doing activities such as inability to squat, physically unable to walk barefoot due to numbness, inability to cut nails, and inability to button clothes and pick up small objects or pieces of paper from the floor. The fingers of the respondents who experience this

stiffness are causing the fingers to not be able to function normally so that the respondent has difficulty if they have to take or hold a small object (Aditya et al. 2021).

The limited social participation of leprosy patients is a result of the physical condition or disability experienced. In the second-degree disability, especially on the hands that experience curly fingers, deformity, and amputations, it results in uncomfortable feelings when the patient interacts and participates with the surrounding environment. The condition was made worse because of the negative stigma in the community in leprosy. Leprosy is often considered a 'dirty and disgusting' disease by the wider community. In fact there are still many who consider leprosy is not a contagious disease but a curse from God due to a dirty body.

Patients with grade 2 leprosy that are accompanied by damage or disability in the hands avoid activities in the wider community even more. They avoid activities such as going to markets, general stores, not being comfortable meeting new people, and not having the same job opportunities as other people. At the research site in Sumberlagah Hospital, Mojokerto, there was a village specifically for leprosy patients so that the condition reduced the number of social participation problems. However, this only applies to leprosy villages only. If a leprosy patient leaves the village, their social participation worsens due to the fear and negative stigma of leprosy patients in the community.

## CONCLUSION

The degree of disability in leprosy clients has a significant impact on the limitations of daily activities carried out by leprosy clients. This is evidenced from 45 people with 2<sup>nd</sup> degree disability, wherein there were 4 people (8.9%) who experienced very severe activity limitations. The degree of disability in leprosy clients has a significant impact on the limited participation made by leprosy clients. This is evidenced from 45 people with grade 2 disabilities wherein there were 24 people (53.5%) who experienced heavy participation limitations, and as many as 1 person (2.2%) who experienced very severe participation limitations.

## RECOMMENDATIONS

A preventive effort by the health department, especially the puskesmas, should provide health

promotion media through the provision of foot exercise exercises.

### ACKNOWLEDGEMENTS

The researchers are grateful to the patients who agreed to participate in this study. The researchers are grateful to the Malang District Health Office and Sumberglagah Hospital, Mojokerto Indonesia for valuable help in collecting the data. The researchers are also thankful to Ronal Surya Aditya for completing this paper.

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**Paper received for publication in May, 2021**  
**Paper accepted for publication in November, 2021**