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## Research Article

# The Relationship of Self Care with Disabilities in People with Leprosy in the South Jakarta

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### Abstract

**Aims:** Leprosy can cause health problem for sufferers. Although it does not cause death directly, leprosy can cause disability that can affect the productivity, social life, economy and future of the sufferer. Efforts are needed to prevent further disability by taking regular self-care. Self-care can be done individually or in groups.

**Methods:** This study uses a quantitative approach with a *cross sectional design*. Sampling using all leprosy patients who were recorded at the registration at 4 Public Health Centers in the South Jakarta area. The total population is 157 people with leprosy. The method of data collection is carried out by interviews and questionnaire.

**Results:** This study provides results that self-care does not stand alone in influencing disability in leprosy patients. But there is an interaction between self-care with the attitude of the patient in performing self-care and the reaction to the treatment given to leprosy sufferers. The variables of self-care, attitudes and reactions to leprosy are variables related to disability in leprosy patients at the Public Health Centers in the South Jakarta area. The most dominant variable related to disability in leprosy patients was self-care ( $p=0.001$  and  $OR=3.381$ ). The OR value for self-care is 3.38, so people with leprosy who do not perform self-care have 3 times the risk of disability. Conclusion: The need for self-care carried out by leprosy patients both individually and in groups to prevent disability.

### Keywords:

**People with leprosy, disability, self-care**

## INTRODUCTION

Leprosy or Morbus Hansen is an infectious disease that causes very complex problems in several countries in the world, including Indonesia. Although it does not cause death directly, leprosy can cause permanent disability which can have a major impact on productivity, social life, the future of the sufferer and of course can threaten the survival of the wider community if the chain of transmission is

not stopped immediately. Disability due to leprosy can also be a burden for sufferers, families and communities, where many sufferers become homeless, socially disabled, unemployed and may lead to crime or disturbance in society. (1)

Based on WHO data in 2016, there were 214,783 new cases detected from 143 countries and 171,948 registered (prevalence rate 0.23 per 10,000 population). Of the number of new cases

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found, the most were in the Southeast Asia region (115,180) followed by the Americas (26,365), Africa (21,465), and the rest were in other regions of the world.

The distribution of leprosy cases in Indonesia spreads to almost all provinces with enclaves in certain districts or sub-districts. Several provinces in eastern Indonesia are still highly endemic provinces. The number of new leprosy cases in Indonesia in 2016 was reported to be 16,826 cases with a prevalence rate of 0.71 per 10,000 population and a new case finding rate of 6.5 per 100,000 population. Among the new cases, 83% were MB (Multi Basiler) cases, 9% were grade 2 disability cases and 11% were pediatric cases. The high proportion of MB cases, grade 2 disabilities and cases of children in Indonesia, shows that transmission is still ongoing and the rate of delay in finding new cases is still high. Currently, there are 11 provinces in Indonesia with a prevalence rate of more than 1 case per 10,000 population. Based on 2016 data, there are still 139 districts/cities with prevalence still above 1/10,000 population (Ministry of Health RI number 308 of 2019). Indonesia is still the third largest contributor to new cases of leprosy in the world with the number of cases ranging from 8% of the world's cases after India and Brazil (WHO, 2017). Based on data obtained by the Disease Prevention and Control Division (P2P) of the DKI Jakarta Provincial Health Office, there were 344 new cases of leprosy recorded since 2018, in 2019 as many as 570 people, in 2020 as many as 321 people and in 2021 as many as 383 people. There is an increase in cases of leprosy, although not as much as in 2019.

Leprosy, if not diagnosed and treated early, can cause defects in the eyes, hands and feet (2). Treatment of leprosy can be done by giving Multi Drug Therapy (MDT). Disability in leprosy can occur during MDT treatment and after completion of treatment (2). Seeing the high rate of disability and the impact of leprosy, it is

necessary to have adequate prevention efforts. Prevention efforts alone are not enough only with MDT treatment because treatment can only kill leprosy germs, but the disability experienced by leprosy sufferers will continue for life (1).

The level of knowledge, early diagnosis, regularity of treatment and self-care are factors that affect the level of disability experienced by patients. The risk of disability in leprosy can be influenced by various factors, including education, type of leprosy, reaction, knowledge, duration of illness, regularity of treatment, diagnosis, self-care, and socioeconomic(3). Efforts that can be made to prevent disability in people with leprosy are self-care(4). Self-care can be used to prevent new disabilities and reduce the severity of existing disabilities(3). Good self-care will be able to prevent or reduce disability in people with leprosy(5). Self-care can be done individually or in groups. One of the programs that have been launched by the government to reduce the occurrence of disability experienced by leprosy clients is to form a KPD (Kelompok Perawatan Diri) or Self Care Group at the Puskesmas. The condition of people with leprosy before the existence of KPD or Self Care Group, they tend to be closed, do not have self-confidence, feel ashamed of their illness and struggle on their own to get health services, and try to find treatment on their own.

After leprosy patients join KPD, patients have a better quality of life compared to leprosy patients who do not join KPD (6). In the South Jakarta area, the Public Health Centers listed as Puskesmas that have a special polyclinic for people with leprosy are the Jagakarsa Public Health Center, the Pancoran Public Health Center, the Pasar Minggu Public Health Center and the Tebet Public Health Center. As for the four puskesmas, the Jagakarsa Public Health Center is a Public Health Center that is used as one of the pilot project Public Health Center in the DKI Jakarta area which has a KPD (Kelompok Perawatan Diri) or Self Care Group.

## METHODS

This type of research is a quantitative study that uses a comparative study method using a cross sectional approach where the researcher wants to compare and find answers fundamentally between two groups, namely a group that does self-care both individually and in groups and a group that does not do self-care. well. The samples taken were all leprosy patients who had received treatment and resided in the study area. Respondents' data were 157 patients, obtained from secondary data registered in the last three years at the Jagakarsa Public Health Centers (69 patients), Pasar Minggu Public Health Centers (24 patients), Pancoran Public Health Centers (36 patients) and Tebet Public Health Centers

(28 patients). The data used in this study are primary data and secondary data. Primary data is data obtained from interviews and observations related to research variables. Obtained from interviews using questionnaires to respondents and observation of disability using a check list related to research variables, namely the type of disability, type of self-care, age, gender, education, occupation, knowledge, attitude, diagnosis, treatment, duration of illness, type of leprosy and leprosy reaction. In addition, information was obtained from the Head of the Self-Care Group (KPD) who was a leper who had recovered. Meanwhile, secondary data was obtained by utilizing existing information in the relevant agencies

## RESULTS

From the univariate analysis, the results obtained are :

### Distribution of the Frequency of People with Leprosy Based on the Level of Disability in the South Jakarta Area in 2014

No	Kategori	n	%
1	Respondent's Age		
	< 15 years old	13	8,3%
	> 15 years old	144	91,7%
2	Gender		
	Male	116	73,9%
	Female	41	26,1%
3	Education		
	Low	16	10,2 %
	High	141	89,8%
4	Type of work		
	Physical work	62	39,5%
	Non Physical work	95	60,5%
5	Tingkat Kecacatan		

	Disable No defect	73 84	46.5% 53,5%
6	Self Care		
	Never/sometimes Continue	52 105	33,1% 66,9%
7	Knowledge		
	Low High	64 93	40,8% 59,2%
8	Attitude in self care		
	Negatif Positif	75 82	47,8% 52,2%
9	Treatment time		
	≤ 12 months ≥ 12 months	23 134	14,6% 85,4%
10	Times		
	≥ 2 years ≤ 2 years	87 70	55,4% 44,6%
11	Kusta Type		
	Multibasilar (MB) Pausibasilar (PB)	134 23	85,4% 14,6%
12	Leprosy Reaction		
	Never Ever	106 51	67,5% 32,5%
	TOTAL	157	100%

From the results of the bivariate analysis of each variable, there are four candidate variables, namely the variables of self-care, work, attitudes of respondents and reactions to leprosy that occur in respondents. From the results of the first analysis of multiple logistic regression, it shows that the job variable has the largest p value of 0.112, so it must be excluded. In the next analysis, the work variable is not included. From the results of the final stage of multiple logistic regression analysis after

the employment variables were excluded, there were no other variables that experienced changes in the OR value > 10%. In the final results of multiple logistic regression, there are three variables that have a p value < 0.05 so that it can be concluded that the variables of self-care, attitudes of respondents and reactions to leprosy that occur in respondents are related to disability in patients. Self-care variable is the most dominant variable related to disability in leprosy patients with

p value = 0.001 and OR = 3.381 so that this variable has a chance of 3 times reducing the level of disability after being controlled by the attitude and reaction variables of leprosy. Which means that there is a risk of disability in leprosy patients who do not perform self-care as much as 3 times compared to leprosy patients who do self-care.

## DISCUSSION

Based on the results of the research conducted, it showed that there was a strong relationship between self-care and disability in leprosy patients with the results of the analysis  $p=0.001$  and  $OR=3.381$ . It can be seen that the problems experienced by people with leprosy are disorders of nerve function in the form of impaired motor function, namely weakness in muscle strength in the eyelids, hands and fingers and toes. Furthermore, there is also impaired sensory function, namely loss of touch sensation in the palms of the hands and feet and fingers. In addition, there is a disturbance of autonomic function, namely the skin becomes dry and cracked due to damage to the sweat glands, oil glands and blood flow. However, the consequences of these problems can be prevented with proper self-care(7). Self care includes eye, hand and foot care. The results of this study are in line with research conducted by (8) on Kijang Island, Indragiri Hilir, Riau which shows there is a relationship between self-care and the incidence of leprosy ( $pvalue = 0.01$ ) and an OR value of 6.3 means that leprosy sufferers who do not take care of themselves risk of experiencing disability 6.3 times higher than those who do not treat. The research conducted by (4) found that there was a relationship between the occurrence of level II disability with good self-care and the patient was at risk of 12 times the occurrence of level II disability. Research conducted by (9) shows that self-care has a direct influence on leprosy disability with a path coefficient value of - 3.80 and  $p<0.001$ . Support from health workers is also needed so that leprosy

patients perform wound care due to leprosy on a regular basis because it will reduce the incidence of new cases of leprosy (10). In addition, the use of technology can be used to empower leprosy patients to take care of themselves (11). Research conducted by (12) ) showed that evaluating the effect of self-care education on awareness, attitude and adherence to self-care behavior in patients showed that patients with self-care education had a lower risk of developing depression.

## CONCLUSION

The conclusion in this study was that there was no significant relationship between disability and age, gender, education, knowledge, diagnosis, treatment, duration of illness and type of leprosy. And there is a significant relationship between group self-care, patient attitudes, work and reactions to leprosy and disability in the South Jakarta area. People with leprosy who do not perform self-care have 3 times the risk of disability compared to those who do self-care. Self-care can be done individually or in groups. The group that continuously helps overcome the problems caused by leprosy is the Self Care Group (KPD). KPD is a group consisting of people with leprosy and former leprosy sufferers. They gather to provide support to each other, especially in preventing and reducing disability as well as finding solutions to problems faced by leprosy such as stigma, discrimination against people with leprosy.

## Suggestion

To prevent the occurrence of disability in people with leprosy in Indonesia in general and in South Jakarta in particular, it should be done by: (a) The need to provide facilities for Puskesmas that do not yet have a Self Care Group (KPD) through advocacy and socialization so that KPD can be used as one of the strategies in preventing disability and as a means of education for the community to prevent stigma and discrimination against people with leprosy. (b) Monitoring or supervision

as well as technical guidance by carrying out the Prevention of Disability (POD) examination conducted by health officers at the Puskesmas, so that defects that occur can be detected as early as possible, especially level 1 disability which is still possible to return to normal by performing regular self-care. (c) Improving health promotion in the form of active promotion to all leprosy patients who are in the area of their Puskesmas. (d) Actively discovering leprosy through activities that are integrated with other programs and (e) Conducting leprosy counseling for sufferers and their families so that they can participate in treatment and self-care to prevent disability.

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