



## Efforts to increase early detection of leprosy patients

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### Abstract

**Background:** Leprosy is an infectious disease which remains a health problem in the community. This study aimed to analyze the relationship between the patients' knowledge, patients' stigma, and patients' access to performance of officers in leprosy early detection

**Materials and Methods:** This study using a cross-sectional approach. The population of this study was 160 people affected by leprosy, with a sample of 113 people.

**Results:** The patients did not have good knowledge and had a positive influence on the performance of officers (B:0.228). Most of the patients stigmatized their illness and had a positive effect on staff performance (B: 0.36). A small portion of leprosy patients' access to health center services was still difficult and had a negative influence on staff performance (B:-0,215).

**Conclusion:** The knowledge and stigma of patients have a positive influence on the performance of officers in leprosy early detection.

**Keywords:** patients' knowledge, patients' stigma, patients' access, performance, leprosy

Setyantari RD, Isasih WD, Ernawaty (2020) Efforts to increase early detection of leprosy patients. Eurasia J Biosci 14: 2727-2731.

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### INTRODUCTION

Leprosy is an infectious disease still considered as a health problem in society as the time needed from transmission to clinical disease takes a long time. The knowledge of society on leprosy is also still low. Thus, most sufferers coming to the health care facilities are already in a state of defective. Defect suffering in people with leprosy causes stigma in society as it is considered as a curse. Hence, the society isolates the sufferers. Problems aroused by leprosy are more complex, not only in terms of medical treatment but also in extends on social, economic, cultural, safety, and national defense (Kementrian, et al. 2015). Leprosy is an infectious disease caused by *Mycobacterium leprae* (*M. leprae*) and can consequently be treated with antibiotics. Freely available long-term multi-drug therapy combining rifampicin, clofazimine, and dapsone effectively targets the bacteria while minimizing the development of drug-resistant strains (Alter, et al. 2008). The 1991 WHO initiative to eliminate leprosy as a public health problem dramatically reduced the global disease prevalence but had only a modest impact on leprosy incidence, suggesting a persisting unknown reservoir. Brazil, Democratic Republic of the Congo, Mozambique, and Nepal have not achieved elimination and account for 23% of new cases (WHO, 2007). Leprosy is common in developing countries. According to World Health Organization (WHO) report in 2016 receiving from 143 countries, the prevalence of leprosy was registered as

0.23 per 10,000 populations with 171.948 leprosy cases on treatment (Partogi, et al. 2018).

Leprosy is usually diagnosed based on clinical examination, supported by slit skin smear, but in certain cases, additional tests needed are histopathology examination, inoculation on the animal, serologic test, and polymerase chain reaction (PCR) (Nasution, et al. 2018). Leprosy is still feared by the community, the patient's family, and leprosy patients themselves due to the lack of wrong knowledge and belief in leprosy and the defects it causes. This view underlies the concept of behavior of the patient's acceptance of his illness, where for this condition, the patients still consider that leprosy is an incurable disease, hereditary disease, curse of God, unclean, and causing disability. Thus, the patients will feel very angry, disappointed or even tend to close themselves, which in the end they not persevering to seek treatment (Kewa, et al. 2014).

Efforts to control leprosy in the world have been set since 2000 as a milestone in achieving elimination. Indonesia succeeded in achieving this target in the same year, but the discovery of new cases during the past 10 years had experienced a static trend, such as the discovery of new cases of leprosy >1,000 cases during the period of 2004-2011 (Kementrian, 2015). In national, East Java Province was in the ninth rank in the finding

Received: October 2019

Accepted: March 2020

Printed: August 2020

of new cases in each 100,000 populations, but when we saw from the number of cases found in East Java, Indonesia contributed the most cases. The discovery of leprosy patients with defect level 2 in East Java is still high. During the period of 2011-2015, it ranged from 12-13%. Likewise, the children cases were raised more than 5% (Kementrian, 2015; Mbah, 2018)

Leprosy is influenced by the high proportion of level 2 defects in some towns or cities. Defect in leprosy sufferers is caused by late discovery and treatment. Leprosy is divided into paucibacillary (PB) and multibacillary (MB). PB patients are those who have a BI lower than 2+, and MB patients are those showing a BI higher than or equal to 2+ (Lastória and de Abreu 2014). Meanwhile, the discovery of new cases of leprosy in Ponorogo experienced some fluctuations almost as same as Case Detection Rate (CDR) ranging between 6-7 per 100,000 population. The cure rate of paucibacillary (PB) had already met the target of  $\geq 95\%$ , while the cure rate of multibacillary still needs awareness. The highest level of disabled leprosy patients' level 2 in East Java province is affected by a high-level proportion of disabled leprosy patients in some counties or cities. The disability of leprosy patients is due to the late detection and treatment (Alter et al. 2008). Lack of knowledge about leprosy and its disability in the society causes patients to experience negative stigma which also This study aimed to analyze the relationship between the patients' knowledge, patients' stigma, and patients' access to performance of officers in leprosy early detection.

## MATERIALS AND METHODS

### Research Design, Population, Samples, and Variables

This was an observational study using a cross-sectional approach. This study was conducted at primary health cares in Ponorogo, East Java, Indonesia, from September 2016 to July 2017. The population of leprosy patients in this study was homogeneous, and there was clear sampling frame of 160 people. The leprosy patients were found and treated in 2014-2016. A sample of 113 leprosy patients were then taken proportionally in 29 randomly selected primary health cares with the highest priority was given to the patients with defect and patients found in the last year. The variables were objects having different size for each different object. The dependent variable of this study was the performance of leprosy officers in an effort to increase the discovery of lepers early, while the independent variable of this study was patients' knowledge, patient's stigma and patient's access.

### Instruments

The data collection technique of this study was a direct interview with a questionnaire guide. The measurement of dependent variable and the

independent variables started with identifying each variable to some indicators, determining the response from each variable, arranging some questions and statements from each variable into questionnaire, until testing the questionnaire with validity and reliability test. The respondents were leprosy primary health care officers, and the interview was conducted directly when the researchers came to the primary health cares. The procedures of data collection, whether it was about dependent variables or independent variables, were done by direct interview to fill in a questionnaire that has been prepared, or the respondents answered the questionnaire by themselves, and it was guided by researchers. Then, it was followed by the editing and coding, compiling data and analyzing, and then drawing conclusion.

### Research Procedures and Analysis

The data collection procedure was implemented by direct interview to fill in the questionnaire. The respondents were given an explanation and then they signed an informed concern. This study has had ethical approval with no: 68-KEPK, issued by the health research ethics committee of the Faculty of Public Health, Universitas Airlangga, Indonesia. Questions and statements were accompanied by answer choices arranged in a multiple-choice format, a Likert scale, and closed questions. The analysis used in this research was descriptive analysis and associative analysis (correlative), in which this analysis was recommended based on the objectives to be achieved. The correlation between variables was analyzed using a ratio scale and tested by multiple linear regression techniques. Then the results of descriptive and correlative analyzes were ranked. The top five rankings were descriptively still a problem (positive value  $< 80\%$ ) and they were determined as a strategic research issue then used as study material in the Focus Group Discussion (FGD) with the health center leprosy officers for 2 hours.

## RESULTS

Based on **Table 1**, it can be seen that the performance of officers during the early discovery of leprosy patients was not good ( $< 20\%$ ) due to the lack of knowledge on leprosy. It can be seen that the performance of officers during the early discovery of leprosy patients was not good ( $< 20\%$ ) since their stigma was still poor against leprosy. **Table 1** shows that the performance of officers during the early discovery of leprosy patients is not good ( $< 20\%$ ) due to the easy access of patients to the primary health cares.

Based on **Table 2**, it can be seen that the patients' knowledge (B:0.228) and the patients' stigma (B:0.036) factors had a positive influence to the performance of officers in finding lepers early, meaning that the better the independent variable, the more dependent variable will increase. Meanwhile, the patients' access variable

**Table 1.** Relationship between the Characteristics of Patients to the Performance of Primary Health Care Leprosy Officers in Ponorogo District In 2017

Patients' Characteristics	Performance						n	%
	Poor		Moderate		Good			
	n	%	n	%	n	%		
Patients' Knowledge:								
a. Poor	0	0	2	100	0	0	2	100
b. Moderate	2	8	16	59	9	33	27	100
c. Good	0	0	0	0	0	0	0	0
Total	2	7	18	62	9	31	29	100
Patients' Stigma:								
a. Poor	2	13	8	54	5	33	15	100
b. Moderate	0	0	6	75	2	25	8	100
c. Good	0	0	4	67	2	33	6	100
Total	2	7	18	62	9	31	29	100
Patients' Access:								
a. Poor	1	6	9	56	6	38	16	100
b. Moderate	1	10	7	70	2	20	10	100
c. Good	0	0	2	67	1	33	3	100
Total	2	7	18	62	9	31	29	100

**Table 2.** Relationship between Patients' Knowledge, Patients' Stigma, Patients' Access to Performance of Primary Health Care Leprosy Officers in Ponorogo District in 2017

Dependent Variable	Independent Variable	B
Performance of officers in finding lepers early.	Patients' knowledge	0.228
	Patients' stigma	0.036
	Patients' access	-0.215

(B: -0.215) had a negative effect on the performance of the officers. It reflects that the better the access of leprosy patients to the health services of primary health care, the lower the performance of officers actively in finding lepers.

## DISCUSSION

The results of the study showed that all leprosy patients treated during the period of 2011-2015 in Ponorogo, Indonesia, did not have good knowledge on leprosy, and they had a positive influence on the performance of officers (B: 0.228). This shows that knowledge related to leprosy has not yet reached the wider community. Lack of socialization is considered to be a factor causing the lack of leprosy knowledge for society. The counseling done by the health center staff regarding to leprosy has been implemented but it only covered limited groups and sometimes it was not implemented on time and did not strike the target. Socialization through mass media and print media is still rarely done. Thus, it causes many people not to understand leprosy. The purpose of the socialization is to improve knowledge and change the attitude and action of patients, families, and communities to support efforts in controlling leprosy (Lastória and de Abreu 2014). The higher and better the knowledge is, the higher the employees' performance as well, and vice versa. Organizational performance from individual aspects becomes essential because individuals must have knowledge relevant to their works (Dewi, et al. 2019).

Also, most patients have high expectation in behavior among medical staff since they are still considered medical staff behavior as poor towards their

patients. The behavior is influenced by three factors: predisposing factor such as knowledge, beliefs, values, attitude; physical environment such as funds, transportation, facilities and government policies; and supporting factor including attitudes and behaviors of community leaders and religious leaders and officers (Tuami, et al. 2018). Usually, patients will come to the health service if they are already in a severe condition. They are treated yet they have not been cured, there are wounds, or there has been a defect. Most leprosy patients only hear leprosy after they are being diagnosed and then they seek further information on leprosy (White and Franco-Paredes 2015). This causes the performance of officers in early detection (Mayberry, 2007). The performance tends to be seen as a result of the work process that is a combination of ability and effort to produce good performance (Rajapathirana & Hui 2018). In health care, patient satisfaction is how much the individual considers health care services or how they are useful, effective, and beneficial, (Mayberry, 2007) including the levels of general health needs and specific needs met, and evaluating patient clinical satisfaction rates for health care, as satisfied patients are more likely to adhere to treatment and are active in their own care (Samad, et al. 2018).

The result of this study showed that the majority of leprosy patients were stigmatized by their illnesses, and it had a positive effect on the performance of officers (B: 0.36). This reflects that the patients' stigma of leprosy affects the performance of primary health care officers in finding patients early, even though the effect is small. The higher the stigma, the more difficult the patient diagnosed in early period, and vice versa. This stigma is related to defect causing patients to suffer psychologically, fear, low self-esteem, isolated and,

finally, they are difficult to find in order to obtain a medication, and they are defected (Siddiqui, et al. 2009). The society also plays a role by avoiding and isolating them as they are afraid to be infected since the leprosy is considered as a curse. In general, the respondents do not know that they are infected by this disease, then they are scared, shocked, and they do not believe it. They even try to commit a suicide (Kaehler, et al. 2015). The problem of stigma in leprosy does not only occur in Ponorogo but also in Indonesia in general. In some countries, it is stated that social stigma is divided into three: *videlicet* a perceived stigma, in which the stigma is suffered more by the society than the sufferers; an enacted stigma in which stigma is experienced and suffered by lepers through discrimination; and a mixed stigma in which the leprosy sufferers are limited by their participation and their activities are generally restricted by the society. The former lepers also experience the same stigma as the leprosy patients (Siddiqui, et al. 2009).

The results showed that some of leprosy patients' access in Ponorogo district in reaching primary health care services was still difficult, including the distance to the primary health care, ignorance on free leprosy medication, a willingness, and a physical ability to visit the primary health care, and those had a negative influence on the performance of officers (B: -0.215). This shows that patient's distance to the health services in the primary health care affects the performance of officers in finding the sufferers early. The more difficult access that the patient has, the higher the performance of officers actively finding patients, and vice versa. Patients who easily reach health services at the primary health care will voluntarily come to the primary health care if they feel the pain. This is included in the leprosy program as a passive discovery, but the performance of the primary health care staff was considered poor. Community access to primary health cares is influenced by: supply, which means the availability of doctors and primary health cares; demand, that is the number of population; and utilization of health service facilities that means physical, economic, and geographical barriers (Roos, et al. 1995).

In the focus group discussion, it is acknowledged that the cause of problems is patients' access which means

the geographical condition of the Ponorogo district, specifically in the mountainous areas, which is difficult to reach health services. The patient's economic condition also does not allow patients to reach the primary health care due to the lack of transportation facilities. The stigma factor also causes sufferers to hide their suffering, so they will not be stigmatized. The community ignorance that free medicine is available at the primary health care is also one of the factors people do not access the primary health care because of the cost factor. Eventually, patients will come to the primary health care when it has already been severed or already in a state of defect. The government has tried to bring health services closer through Community-Based Health Efforts, such as integrated guidance post for infants. However, due to lack of community knowledge on the early symptoms of leprosy, they do not access health care facilities because they consider it an ordinary disease (Peters, et al. 2013).

There are many factors that are likely to influence the performance of the primary health care leprosy officers in finding lepers early to reduce the proportion of level 2 defect in new cases of leprosy in Ponorogo district, such as individual staff factors, primary health care organizational factors, health service factors, and patient factors. This study was covered only to patient factors consisting of patients' knowledge, patients' stigma, and patients' access.

## CONCLUSION

The knowledge and stigma are still a problem, while patients' access to the primary health care is good. Knowledge and stigma of patients have a positive influence. For instance, lack of knowledge and bad stigma will reduce the performance of officers in finding lepers early. Patients' access has a negative influence as the good access will reduce the performance of officers in finding lepers early.

## ACKNOWLEDGEMENT

We would like to say thank you so much to all of respondents that really cooperative to join in the research and head of primary health care that support the research very well.

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