

Perspective Model Secondary Prevention of Leprosy in Mojokerto, East Java, Indonesia

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Abstract: *Leprosy is a public health problem in Indonesia. East Java is first ranked as the largest contributor of leprosy cases in Indonesia. Leprosy is still high disability figures, therefore secondary prevention of leprosy need to be researched further in order to decrease morbidity and disability. This study aims to design a model of secondary prevention of leprosy. Methods: This study was an observational study with cross sectional. The sample of 50 families who live with lepers in Mojokerto is taken by simple random sampling. Data retrieved by interviews using questionnaires, and observation sheet further processed by descriptive and gradual regression with an alpha of 0.05. Result: Research results indicate that there is an influence of knowledge on family attitudes ($\beta=0.237$, $p=0.040$), family stigma against family attitudes ($\beta=-0.406$, $p=0.001$) and social support towards family attitude ($\beta=0.401$, $p=0.001$); knowledge influence towards subjective norm ($\beta=0.331$, $p=0.019$), there is an influence of social support on collective efficacy ($\beta=0.388$, $p=0.005$), there is an influence of family attitudes toward discrimination ($\beta=0.592$, $p=0.000$), there is effect of subjective norm on secondary prevention ($\beta=-0.277$, $p=0.045$) and discrimination against secondary prevention ($\beta=-0.317$, $p=0.022$). Analysis: It is concluded that the secondary prevention of leprosy is a new finding, in which the secondary prevention of leprosy influenced by subjective norms and discrimination. Discussion: Subjective norm is reduced or eliminated, family discrimination eliminated by increasing the positive attitude of families through increased knowledge about leprosy, eliminated stigma and increased social support through advocacy and group counseling leprosy.*

Keywords: Secondary prevention models, Leprosy, Subjective norms, Discrimination

1. Background

Leprosy is a disease caused by *Mycobacterium leprae* that attack humans. Throughout the history of leprosy has been feared and misunderstood, leprosy was considered a hereditary disease, a curse or punishment from God. Even after the discovery of the bacterium that causes leprosy, people who experience stigma against leprosy and shunned by society (Hiswani, 2001).

Leprosy is a public health problem. The problems caused by leprosy are very complex in terms of not only medical but extends to social, economic, cultural, security and national defense (Health Department of RI, 2006). Leprosy until now is still a public health problem in 17 countries around the world. The number of new cases in 2010 is 228,474 (WHO, 2011). Indonesia is the third rank in the world after Brazil, with national prevalence of patients already under one per 1,000 populations or 0.91 per 10,000 populations and the number of disability due to leprosy, second level of 10.37% in Indonesia, especially in children (Health Ministry of RI, 2011). East Java Province ranked first in Indonesia as the largest contributor to the national leprosy cases. East Java is a high endemic area where leprosy prevalence rate (PR) over 1 per ten thousand population. East Java Provincial Health Office also has not been able to meet the target of reducing the level of disability. Target new disability leprosy patients nationwide are 5%, although East Java, the figure is still 14%, or nearly three times the national target. Public awareness to recognize early symptoms of leprosy still less so lepers found often already in a state of disability.

Disability due to leprosy can cause stigma. Therefore leprosy is still feared the people, including most family health workers. Stigma affects various aspects of life of people

affected by leprosy, including mobility, interpersonal relationships, marriage, work, leisure activities, and attendance at social and religious functions (Eremugo E., 2010).

People with stigmatized conditions can hide or deny their condition and delay treatment, so it will result at the disease, causing more severe diseases and increased risk of complications, increase disease transmission in the community, making it difficult to track the whereabouts of patients who failed treatment of leprosy. Some patients may not adhere to treatment when diagnosed because it takes a long time, and drug resistance will cause a burden on health services (Eremugo E., 2010). Disability issues, stigma, social discrimination are still a problem for the disabled leprosy (Health Department, 2006).

The issues mentioned above need to act or leprosy prevention efforts. Secondary prevention efforts with regard to the detection of the disease at an early stage before symptoms appear, interventions to slow or stop the progression of the disease, proper treatment and disability restrictions.

Community and family support becomes very important, because community influence strong in patients that have had a positive attitude towards people with leprosy. By changing the behavior that is expected positive families and communities involved in the prevention of leprosy. Therefore secondary prevention model of leprosy is expected to help solve leprosy, which is still a public health problem. If prevention of leprosy conducted jointly among patients, families, communities and health workers are expected to be more successful in preventing disease called collective efficacy.

This study aims to design models in secondary prevention of leprosy. It is expected that the results of this theoretical study as an explanation model of secondary prevention of leprosy and to reduce discrimination against leprosy patients. Besides its practical benefits are as basic health promotion in the prevention of leprosy by focusing on demographic, social support and environment.

2. Research Design

This research is observational and analytical study research design was *cross-sectional*. The definition of research *cross-sectional* design is each subject observed only once and the measurement variable subject conducted during the examination. Thus can be explained which is study the researchers take measurements on aspects related to the secondary prevention of leprosy by the family naturally or it is a one-time measurement.

Population in this study was all families who live with lepers in the area of Mojokerto, amount 68 people (Health Department of Mojokerto, 2011). The samples in this study are some of the eligible population inclusion criteria. The criteria of inclusion is one of the family members of patients with leprosy is in the region of Mojokerto (fathers/mothers/children), aged > 17 years old, live with lepers and willing to be a respondent. Sample size in this study using Cochran formula on "*Sampling Technique*" (New York: John Wiley & Sons Inc., 1977) of 50 respondents. Meanwhile its sampling technique is *simple random sampling*.

Variables examined included: 1) independent variables: knowledge about the leprosy disease, stigma family and social support, 2) inter-dependent variable: family attitudes, subjective norms and collective efficacy; 3) dependent variable: discrimination and secondary prevention.

Data retrieved by interview using a questionnaire that had been tested for validity and reliability, as well as the observation sheet. The study was conducted in February through May 2013. Data processed by descriptive and gradual regression with an alpha of 0.05 to test hypothesis research.

3. Result

In this section, the data presented on the results of research on models of secondary prevention of leprosy in Mojokerto East Java Indonesia.

Characteristics of respondents

Table 1: Characteristics of Respondents based on Age, Gender, Length of Stay Housemate, Family Type in Mojokerto 2013

Characteristics of Respondents	Frequency	%
21-40	24	48.0
41-60	21	42.0
> 60	4	8.0
Total	50	100.0

Gender:		
Male	14	28.0
Female	36	72.0
Total	50	100.0
The length of staying at the same home		
<2 years	0	0.0
2-4 years	6	12.0
> 4 years	44	88.0
Total	50	100.0
Type Family		
Nuclear family	42	84.0
Extended family	8	16.0
Total	50	100.0

Data Source: Primary Data 2013

Table 1 shows that most of the respondents aged between 21-40 as 24 people (48.0%), female 36 people (72.0%), the majority of respondents (44 people or 88.0%) more than 4 years live with lepers, and the majority of respondents (42 people or 84.0%) a nuclear family.

Table 2: Distribution of Respondents Knowledge About the Leprosy disease, Family Stigma, Social Support, Attitude, Subjective Norms, Collective Efficacy, Discrimination and Secondary Prevention of Leprosy Discrimination In Mojokerto 2013.

Characteristics of Respondents	Frequency	%
Knowledge About The Leprosy Disease		
Not good	22	44.0
Less	12	24.0
Enough	5	10.0
Good	11	22.0
Total	50	100.0
Stigma family		
Low	16	32.0
Moderate	25	50.0
High	9	18.0
Total	50	100.0

Data Source: Primary Data 2013

Characteristics of Respondents	Frequency	%
Social Support		
Less	4	8.0
Enough	46	92.0
Total	50	100.0
Family Attitude		
Not good	6	12.0
Less	19	38.0
Enough	24	48.0
Good	1	2.0
Total	50	100.0
Subjective Norms		
Moderate	2	4.0
High	43	86.0
Very high	5	10.0
Total	50	100.0
Collective Efficacy		
Not good	2	4.0
Less	1	2.0
Enough	20	40.0
Good	27	54.0
Total		
Discrimination		
Moderate	7	14.0

High	27	54.0
Very high	16	32.0
Total	50	100.0
Secondary prevention		
Not good	1	2.0
Less	3	6.0
Enough	29	58.0
Good	17	34.0
Total	50	100.0

Data Source: Primary Data 2013

Based on Table 2 known that most of the respondents (22 people or 44.0%) do not have good knowledge about the leprosy disease, family stigma about leprosy is currently 25 people (50.0%), family social support to people with leprosy is enough, as many as 46 people (92.0%). Known that most of the respondents (24 people or 48.0%) have good enough attitude to the leper, but subjective norm respondents about the disease is high, with 43 people (86.0%) and collective efficacy respondents about leprosy is good, as many as 27 people (54.0%). Besides, it is known that most of the 27 people (54.0%) have high discrimination on the family members who suffer from leprosy but secondary prevention is sufficient (29 people or 58.0%).

4. Analysis of the Results.

Table 3: Analysis Results of Statistical Regression

No.	Influence between variables	β	Sig	Information
Path I				
1	Knowledge towards family attitudes	0.237	0.040	Significant
2	Stigma family towards family attitudes	-0.406	0.001	Significant
3	Social support towards family attitudes	0.401	0.001	Significant
Path II				
4	Knowledge towards subjective norm	0.331	0.019	Significant
5	Family stigma towards subjective norm	0.222	0.106	Not Significant
6	Social support towards the subjective norm	-0.012	0.929	No significant
Path III				
7	Knowledge towards collective efficacy	-0.013	0.925	No significant
8	Stigma towards collective family efficacy	-0.002	0.987	No significant
9	Social Support towards collective efficacy	0.388	0.005	Significant
Path IV				
10	Attitudes towards discrimination	0.592	0.000	Significant
11	Subjective norm towards discrimination	-0.063	0.597	No significant
12	Collective efficacy towards discrimination	0.072	0.550	No significant
Path V				
13	Attitudes toward secondary prevention	0.029	0.873	No significant
14	Subjective norms towards secondary prevention	-0.277	0.045	Significant
15	Social support towards secondary prevention	0.141	0.329	No significant

16	Collective efficacy towards secondary prevention	-0.025	0.864	No significant
17	Discrimination towards secondary prevention	-0.317	0.022	Significant

Data Source: Primary Data 2013

5. Discussion

People with leprosy are not handled properly can suffer permanent physical disability. Process leprosy occurrence of defects allegedly is caused by direct infiltration of M. Leprosy to the edge of the nervous system and leprosy reactions (Health Department of RI, 2006). As a result of leprosy disability, families are burdened psychologically influencing in attitude which is a feeling of support or favor or feeling without support and taking sides (*unfavorable*) on the object (Barkowitz, 1972; in Azwar, 2012). Personal factor experience is the basis of personal attitude. Permanent disability of family member experienced very deep emotions that become a solid foundation in the form of family attitude with leprosy.

Attitude is a constellation of components of cognitive, affective and psychomotor aspects of leprosy treatment, interacting understanding, feel, and behave toward an object (Azwar, 2012). If we look to the theory above, the attitude of the leper family is essentially interaction between the cognitive component (understanding of leprosy), affective (emotional involvement / feeling of family in the face of leprosy problems experienced by their family) and conative (psychomotor aspects of leprosy treatment).

The relation between knowledge and attitudes in this study accordance to the theory of Azwar (2012) which states that one of the three components of attitude structure is the cognitive component. The cognitive component related to belief, the idea and concept. Knowledge was instrumental in establishing the concept of a person. By having a good understanding about the disease which will affect a positive attitude on the prevention and treatment of leprosy.

The results of study indicate influencing of the family towards family attitudes stigma of leprosy patients, meaning that the higher family stigma, family attitude is worse. Stigma according to Sociologist Erving Goffman is an attribute highly discredited individual. The values and believes can play a powerful role in creating or maintaining stigma (Bhawan N., 2009). Society facts show that most patients with untreated leprosy will end up with a disability. This condition causes a fear of causing leprosy patients stigma and discrimination (Eremugo. E, 2002). According Bhawan, N (2009) is stigma is a negative response to the differences in human beings.

The results of the study indicate there is effect of social support on the attitude of the family. Factors that are likely to support this research data showed that most respondents have longer life at the same home with leprosy patients over 4 years, total of 44 people (88%). Togetherness is a relatively long time to grow a strong emotional attachment between family members. This is in line with the theory expressed by

Friedman M, Marilyn (1992) which is a family is a collection of two or more persons who live together with the rules and the emotional attachment and each individual has a role which is as part of the family. At the core of the family in general affective functions related to internal functions family, which is the basis of the strength of the better family. Affective functions useful for the fulfillment of psychosocial needs.

Social support used in health studies to improve social relations component. Forms of social support include: 1) emotional support, namely: empathy, love, trust, and caring; 2) Instrumental Support, which is a real help in the form of money, goods and services that directly help someone in need and; 3) support information is the provision of advice, suggestions, direction, and the feedback about the individual situation so it can be used to overcome the problem. This informative support is important when there is a lack of knowledge and skills related to disease prognosis.

Factors that influence a person's attitude is the one that is considered important (*significant others*) that supports the existence of sufferers (Azwar, 2012). The people that are considered as important people can improve social support to people with leprosy.

Personal knowledge embedded in individual experience and involves intangible factors such as personal belief, perspective, and value systems. Beliefs, perceptions, ideals, values, emotions and mental models of exist in a person (Nonaka & Takeuchi, 1995). Therefore it can be concluded that the values or norms become part of the knowledge. The higher knowledge, the more closely related to a person's subjective norm because subjective norm is the combined knowledge covers a number of things that one has such experience, beliefs, values, motivation and information. Subjective Norms reflect social influence means perceptions regarding difficult or easy for someone to show a certain behavior and assumed to reflect past experiences and their experienced hindrance or obstacle. Aspects of subjective norm studied in this research are the view of the family of the perceived social pressure of leprosy.

The fact that most of those with untreated leprosy ended with disabilities (Eremugo E., 2010). People still think that leprosy is a disease which is scary. Fear of leprosy mainly with disability causes of stigma and discrimination. According ILEP (2011) stigma is a negative response to the differences in human beings. Stigma is "a social process that occurs when elements of labeling, stereotyping, separation, status loss, and discrimination occur in a power situation (Eremugo. E, 2010).

The stigma of leprosy greatly affects aspects of life such as social status, employment or occupation, marriage and family dreams. The impact is felt by the individual, community, public health program and treatment (ILEP 2011; Eremugo. E, 2010). The stigma against leprosy turns in this study did not reveal any influence on collective efficacy. People are still convinced that their efforts together in the prevention of leprosy can lead to positive change.

Understanding stigma development process is very important to plan a strategy to reduce stigma. Researchers argue that the stigma against leprosy need treatment involves a comprehensive and cross-cutting. Treatment program ranges from an increased understanding of leprosy (cognitive aspect), efforts to foster a sense of empathy for the patient and family (affective aspects), as well as real effort of prevention, treatment, rehabilitation and empowerment especially lepers who have experience of disability (conative aspect).

The results of study showed there is effect of social support towards collective efficacy. The influence of social support toward collective efficacy because the social support may increase the components such meaningful social relationship in collective efficacy. A family needs for mutual support among all members of the family. People who live in supportive environments may support their mental health condition better than those who live without support. Family social support can affect a person's health adaptation (Friedman. M, Marilyn (1992).

Behavioral prevention of leprosy needs to be grown on family life with leprosy. According to Waithaka, P. (2007) leprosy prevention refers to the action to halt or delay the progression of the disease from stages namely: primary prevention, secondary and tertiary. Application of the secondary prevention of leprosy patients who already have the disease is to prevent the recurrence or exacerbation. Secondary prevention aims to prevent damage and avoid the complications of the disease.

Prevention is part of any leprosy control program. Based on leprosy prevention handbook (Health Department of RI, 2006), there are several attempts to defect prevention, namely: early detection of leprosy patients before disability, the treatment of patients with Multi Drug Therapy (MDT) until Release From Treatment (RFT), early detection of leprosy reaction by checking function nerves routinely, handling response, counseling, self-care, use of assistive devices and medical rehabilitation (reconstructive surgery). Early detection of nerve damage and measures is to prevent deformity. The best way of prevention of disability or Preventive of Disabilities (POD) is to carry out early diagnosis and treatment of leprosy MDT is a fast and accurately (Juanda, A., 2007). This secondary prevention aims to prevent damage and avoid the complications of the disease. These actions include: early diagnosis, screening and appropriate treatment.

Behavior of health prevention is any activities undertaken by someone prevent or detect disease in asymptomatic state. This behavior is intended to minimize the effects of the disease. Preventive health behavior is generally associated with the belief that such behavior would benefit health. Subjectively norm is the family views towards perceived social pressure about leprosy like keep away from the patients, fear of infection, exclusion of the work and activities in the community. Thus implies higher perceived subjective norms family then the family will be shier and did not take steps to prevent secondary. As a result of enormous

pressure from society on families make it increasingly indifferent or apathetic towards the prevention of leprosy.

Secondary prevention of leprosy models depicted in Figure 1.1 that has never existed before, therefore it was concluded that this model as a new finding in the secondary prevention of leprosy. Secondary prevention is influenced by two factors, namely discrimination and subjective norm. Discrimination is influenced family attitudes about leprosy, which factors contributed to the change in attitude is a family of knowledge about leprosy, stigma family and social support. Subjective norm families are influenced by family knowledge about leprosy. Social supporting influences on collective efficacy.

So if we do secondary prevention of leprosy, there are two attempts to lose the family subjective norms and eliminate or reduce discrimination by increasing positive attitude families through increasing knowledge about leprosy, lowering or eliminating the stigma of leprosy patient families, as well as improve social support family.

6. Conclusion

Based on the results of research and discussion on the model of secondary prevention of leprosy then concluded as follows:

- 1) The family attitudes on a leper are affected by a family knowledge about leprosy, stigma about leprosy and social support in patients with leprosy. Then this attitude will affect discrimination which will contribute to the secondary prevention of leprosy.
- 2) Subjective norm of families is affected by a family of knowledge about leprosy. Subjective norms contribute to the secondary prevention of leprosy
- 3) Family social support includes emotional support, instrumental and information influences collective efficacy.
- 4) Model of secondary prevention of leprosy is a new discovery indicates that secondary prevention of leprosy affected by two (2) factors, namely discrimination and subjective norm.

Based on the conclusions of this study, the following is presented some suggestions as follows:

- 1) Model of secondary prevention of leprosy should be tested and further developed by the parties concerned, especially the Ministry of Health in addressing the problems of secondary prevention of leprosy.
- 2) Family subjective norms should be reduced or eliminated include: increasing knowledge about leprosy, eliminating the fear of contracting leprosy, not segregate leprosy patients, provide employment opportunities to people with leprosy according to ability or expertise, engage in community activities, and does not refused lepers .
- 3) Family discrimination must be eliminated by increasing the positive attitude of family through: increased knowledge about leprosy, eliminating stigma and enhancing social support through advocacy and group counseling leprosy.

- 4) It is important to increase collective efficacy beginning of the optimization of social support from family leper further extends to the whole of societies.

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