Factors Contributing to Leprosy Stigma among Madurese People

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ABSTRACT

Leprosy is a disease that still has a stigma in society. Leprosy patients are considered have a curse from God, so they must be shunned, are incurable and are disinherited. This study aimed to identify the factors contributing to the leprosy stigma among the Madurese people in Indonesia. This was a descriptive analytical study with a cross-sectional approach that involved 107 adult people living around leprosy patients obtained through simple random sampling with other certain criteria. The variables measured were education, economic status, regulations and policies, cultural values and lifestyle, the family and social factor, the religious and philosophical factor, technology and leprosy stigma. The data was collected using a questionnaire and analyzed using the Spearman Rho test ($\alpha=0.05$). The study revealed that education, economic level, regulations and policies, cultural values and lifestyle, the family and social factor, the religious and philosophical factor and also technology had a significant correlation with leprosy stigma ($p=0.011$; $p=0.02$; $p=0.008$; $p=0.011$; $p=0.015$; $p=0.000$; $p=0.0037$). It is expected for the government and health workers to conduct socialization and counseling focused on leprosy, therefore allowing people to be able to understand the disease, thus lowering the leprosy stigma.

Keywords: leprosy stigma, madurese people, education, economic factor, cultural values.

Introduction

Leprosy is a disease that still has a stigma within the community. The stigma arises because of the false perception of leprosy. Many people still think that leprosy is caused by a curse or witchcraft, that it is a punishment from God, sin, eating certain types of food or inherited.[1] Wrong beliefs in the community have continued to expand until now, thus affecting the self-confidence and social function of leprosy patients.[2] This study aimed to determine the factors associated with the emergence of stigma in the Madurese people based on their beliefs and culture.

The World Health Organization (WHO) reported in 2015 that there were 210,758 new lepers and that Indonesia ranks the third largest focus of leprosy cases in the world after India and Brazil.[3] Throughout 2013, the Indonesian Ministry of Health recorded 16,825 new leprosy cases with a disability rate of 6.82 per 1,000,000 people.[2] In addition, the East Java Health Office reported that in 2015, there were 3,835 cases consisting of 3,506 adult patients and 329 cases where the patients were children.[4] The distribution of leprosy cases in East Java based on leprosy type was 498 PausiBasiler (PB) and 3,337 Multi Basiler (MB). Based on the Bangkalan Regency Health Profile in 2015, the number of new leprosy cases was 310. This number has increased from the previous year.[5] One of the biggest leprosy case contributors is the Burneh Health Center work area. Based on the data from the Burneh Health Center, the number of new case findings in 2014 was 12 lepers, increasing in 2015 to as many as 22 lepers and more in 2016, up to 38 lepers.

Bangkalan Regency is an area that still has many leprosy sufferers. This is influenced by the condition of Bangkalan regency, which is mostly made up of slum areas. The spread of leprosy in the Bangkalan area not only affects the ongoing health conditions but it also affects the social and economic conditions. The results

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of the preliminary study focused on 8 randomly selected respondents on April 2017 showed that there is still a negative perception (stigma) felt by the leprosy patients from the community. Some unpleasant events related to the stigma can occur, such as 1) when a man with leprosy attended the congregational prayer, other people stayed away from him; 2) a woman with leprosy is not married -although she wanted to- because she is ostracized by the community and confined herself to her home until she was finally able to escape to Kalimantan Island; 3) a teenager with leprosy refuses to go to school because he is bullied and thought of as strange by his friends and 4) two patients dropped out of a treatment regime because they were embarrassed and felt the stigma even from the health workers. Therefore, it is necessary to identify why the stigma is still high in the community, so then in the future, an appropriate intervention can be formulated to overcome this problem.

Method

Study Design, Setting, and Sampling: This study was descriptive using a cross-sectional approach. The population in this study consisted of the community living around people with leprosy in the same area (1-2 km in distance) in Bangkalan Regency, as many as 146 people; 107 respondents were selected through simple random sampling.

Study Variables: The variables measured included education, economic status, regulations and policies, cultural values and lifestyle, the family and social factor, religion and philosophy, technology and the leprosy stigma.

The education and economic factors were measured using a questionnaire. The questionnaire focused on regulations and policies, cultural values and lifestyle, social life and family, religion and philosophy and technology was modified from transcultural theory.[6] The stigma questionnaire is a modification of the questionnaire on community stigma used in studies focused on HIV/AIDS sufferers.

Data Analysis: A descriptive statistics method was employed to analyze the data in order to generate the study results in the form of frequencies, percentages, mean, ranges and standard deviation. This method allowed us to summarize the characteristics of the study subjects based on the variables selected. The data was analyzed using the Spearman Rho correlation test with a significance level of ≤ 0.05.

Results

To begin with, 107 respondents were residents obtained from the community around known lepers. Table 1 presents the characteristics of the respondents included in this study. All of the respondents were adults with an age range of 26 - 35 years old for the majority (55.1%). Most of them (64.4%) were female. In addition, most of respondents were farmers (42%) and unemployed (25.2%).

Table 1: Characteristics of the respondents (n = 107)

Demographic variables	f (x)	%
Age		
17-25 y.o	18	16,8
26-35 y.o	59	55,1
>35 y.o	30	28
Sex		
Female	69	64,4
Male	38	35,5
Occupation		
Unemployment	27	25,2
Government employee	5	4,6
Farmer	45	42,0
Private employee	8	7,4
Entrepreneur	16	14,9
Temporary employee	6	5,6

Table 2 displays the distribution of each of the variables measured in this study and the statistical results. It was found most of the respondents had graduated from elementary school and that 21 respondents had a negative stigma. In addition, the statistical test results showed p = 0.011 (p <0.05), so there was found to be a significant relationship between the level of education and the leprosy stigma in the community. In line with the previous results, other factors (economic, regulatory and policy, cultural and life value, social and family, religious and philosophy and technology) also showed a significant relationship with the emergence of leprosy stigma in the community with a value of p <0.05 respectively (see table 2). In fact, all of the variables also showed a weak to strong correlation.

Table 2: Cross tabulation and statistical results (n = 107)

Variable	Stigma		Statistical result
	Positive	**Negative**	
Education			
None	15	6	p = 0.011 r = 0.244
Elementary	17	21	
Junior high school	8	12	
High school	9	13	
Higher education	4	2	
Total	53	54	
Economic			
<Bangkalan minimum wages	20	38	p = 0.023 r = 0.220
≥ Bangkalan minimum wages	22	27	
Total	42	65	
Regulation and policy (perceived support)			
Positive	32	22	p = 0.008 r = 0.257
Negative	7	46	
Total	39	68	
Cultural and life value			
Positive	25	13	p = 0.011 r = 0.245
Negative	29	40	
Total	54	53	
Social and family (perceived support)			
Positive	31	18	p = 0.015 r = 0.235
Negative	21	37	
Total	52	55	
Religiosity and philosophical value			
Positive	26	9	p = 0.000 r = 0.349
Negative	28	45	
Total	54	54	
Technology (perceived support)			
Positive	26	14	p = 0.037 r = 0.202
Negative	27	40	
Total	53	54	

Discussion

Based on the data that has been conveyed above, the following will be discussed about the relationship of each of the factors studied according to the purpose of the study, which is to explain the factor analysis related to the emergence of leprosy stigma in the community based on the theory of transcultural transmission at Burneh health center in Bangkalan Regency.

The respondent's distribution data based on the economic factors showed that the majority of the respondents had an less economic status with an income below the Bangkalan minimum wage, which was < Rp. 1,530,655.00 for as many as 38 (35.5%) respondents. The economic relationship with leprosy stigma showed there to be a correlation coefficient of 0.220, thus indicating there to be a weaker correlation strength. The lower the economic income of the community, the higher the stigma that the community has. Economic factors are one of the important things related to someone providing good support. Friedman and Leininger stated that the higher the level of economic status, the more support and decision-making can be provided in the treatment of lepers. A person will utilize the material resources that are owned by them to finance his illness so then he can get well soon. The factors that influence a person's economic status include education, employment, income, economic conditions and cultural background.[7,8]

In relation to the regulatory and policy factors, the results of the statistical test showed the factors as having a significant correlation with the leprosy stigma in the community. The regulatory and policy factors yielded that almost half of the respondents had negative rules and policies, namely that 46 (42.9%) of the respondents had a negative stigma. The relationship between regulations and policies with the leprosy stigma showed a correlation coefficient of 0.257, which indicates a weak correlation strength. The more negative values that the regulations and policies that people have, the lower the stigma of the community. According to the theory of transcultural nursing by Leininger (2002), it explains that the hospital policies and regulations that are applied and that everything that affects individual activities in cross-cultural nursing care.[8] In this study, there were no government regulations and policies relating to leprosy.

Based on the results of the research that has been conducted on the cultural and life values factor, the majority of the respondents have a negative value for cultural values and lifestyle in relation to the emergence of the leprosy stigma in the community for as many as 40 (37.3%) respondents. The negative cultural values and lifestyle of the respondents stated that, from the beginning, they thought that leprosy had to be shunned, that it was a hereditary disease and that it could spread throughout the community. They assumed that leprosy is a frightening disease. According to transcultural theory, culture is the norm of the actions of the group members

who are being studied, who can then be divided and provided instructions for thinking, acting and making decisions. In this study, there was a relationship between cultural values and the emergence of leprosy stigma in society.[8] The results of this study are in line with the theory of transcultural nursing, where culture and lifestyle are factors that are very influential concerning a person's actions.[8,9] The respondents who have the stigma of leprosy are influenced by their habits, as well as the beliefs that have become the rules of life of a region, where most of the cultural and lifestyle factors have a tendency towards displaying negative behavior towards leprosy. According to the researchers, cultural values and lifestyles are closely related to the emergence of leprosy stigma in society. If the culture adopted by the individuals or related groups in daily life is not good, then this will affect the behavior of the individuals or groups in viewing and treating lepers. This can be seen from societal habits or culture, where many people still think that leprosy is a disgusting disease; a disease that must be shunned, even to the point where leprosy is considered to be a hereditary disease. The higher the cultural values and lifestyle that the community has, the lower the stigma.

The respondent distribution data based on the social and family factors showed that most of the respondents had negative values regarding the social and family factor in terms of the occurrence of the leprosy stigma for as many as 37 (34.5%) respondents. The social and family factors that are inherent in the community to date, so if they are suffering from leprosy then it is kept a secret because of a fear of their neighbors or people who they know. People who suffer from leprosy are exiled or confined to a room and there are still many people who stay away from lepers because they are afraid of contracting the disease. Pierce defined social support as a source of emotional, informational or mentoring support provided by people around individuals both in the neighborhood and in the community to deal with every problem and the crises that occur in everyday in life.[10] Based on the results of the study, the results indicate that that there is a relationship between the social and family factors towards the emergence of the leprosy stigma in the community. Familial social support is still bound by the habits, customs, and beliefs of the family or community, thus causing a negative perception of leprosy. The higher the social and family factor owned by the community, the lower the stigma that they have.

The results of the data on the religious and philosophical research that has been conducted by the researchers indicated that most of the respondents have a negative value regarding their religious and philosophical factors, as many as 43 (40.1%) respondents. People still think that leprosy is caused by a curse from God, from eating wrong and also by rarely worshiping. According to the transcultural theory of nursing, religiosity provides a very strong motivation to place the truth above all else, even above a person's own life. This causes a person to have a humble nature and open sense of self.[8] Religiosity and philosophy includes the existence of a religion that is embraced, as a way of looking at the disease and as a method of treatment involving religious habits that have a positive effect on health. It is known that there are three dimensions involved in the religiosity of the Madurese. The experience dimension is about feeling calm when doing religious actions. The dimensions of religious knowledge is focused on beliefs that are described by tradition. The frequency dimension is about what the impact will be after doing a religious action, between the bad and good effects.[11]

The research results showed that there is a relationship between religion and philosophy with the emergence of the leprosy stigma in society. The respondents thought that leprosy could be caused by a curse from God because of the sins of the individual, because of a curse or because he rarely worshiped. Some thought that leprosy could only be cured by a shaman or a traditional medicaster, or by religious leader referred to as a "kyai". The higher the strength of the religious philosophy that the community has, the lower the stigma it has.

The respondent's distribution data based on technological factors showed that most of the respondents had less technology, with as many as 40 (37.3%) respondents answering negatively. This was due to the lack of knowledge of the respondents in terms of utilizing or obtaining health and/or electronic technology. Therefore how the respondents get their information about leprosy is lacking. Even today, there has never been any form of offered counseling about leprosy either from the government or from the puskesmas.

According to the theory of transcultural nursing, technological factors are one of the factors that influence individual behavior based on culture. Health technology is an infrastructure that allows individuals to choose or get offers to solve problems within the health services.

The utilization of health technology is influenced by the attitudes of the health workers, paired with the needs and interests of the community. Technology refers to all forms of technology used to create, store, change and use information in all its forms.[8,12]

Conclusion

The variables that significantly correlate with the emergence of leprosy stigma in the community in the Burneh health center in Bangkalan Regency are educational factors, economic factors, regulatory and policy factors, cultural values and lifestyle factors, social and family factors, religious and philosophical factors and also technological factors. It is expected that the Burneh Community Health Center in Bangkalan Regency will conduct socialization and counseling on the causes and transmission of leprosy in each hamlet or village. This is so then people can better understand what leprosy is and how it is transmitted.

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