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Perceived Stigma in People Affected by Leprosy in Leprosy Village of Sitanala, Banten, Indonesia

Perceived Stigma pada Orang yang Pernah Mengalami Kusta di Perkampungan Kusta Sitanala, Banten, Indonesia

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Abstract

Leprosy is a disease among neglected tropical diseases (NTDs) that becomes a global problem. This disease causes the perceived stigma among people affected. This study was aimed to determine the most dominant factor affecting perceived stigma in people affected by leprosy in leprosy village of Sitanala, Tangerang District, Banten Province, Indonesia. Secondary data were used and taken from cross-sectionally, and samples were selected by purposively sampling. Results of the study showed that factors related to perceived stigma were education level, perception of knowledge about leprosy, level of disability, and cultural values. There was modification effect between the level of disability and perception of knowledge about leprosy, (OR_1=4.82 (95% CI = 1.26-18.34) and OR_2=1.18 (95% CI = 0.2-6.98)). The most dominant factor is education level (PAR% = 38.8%).

Keywords: Leprosy, perceived stigma, Sitanala

Abstrak

Kusta merupakan penyakit *neglected tropical diseases* (NTDs) yang menjadi masalah global. Penyakit ini menyebabkan *perceived* stigma pada orang yang mengalaminya. Penelitian ini bertujuan untuk mengetahui faktor yang paling dominan memengaruhi *perceived stigma* pada orang yang pernah mengalami kusta di perkampungan kusta Sitanala, Kabupaten Tangerang, Provinsi Banten, Indonesia. Data yang digunakan berasal dari survei potong lintang dari sebuah tesis yang bertujuan untuk menentukan faktor yang berhubungan dengan *perceived stigma*, sampel dipilih secara *purposive sampling*. Hasil penelitian menunjukkan bahwa faktor-faktor yang berhubungan dengan *perceived stigma* adalah tingkat pendidikan, persepsi pengetahuan tentang kusta, tingkat kecacatan, dan nilai budaya. Terdapat efek modifikasi antara tingkat kecacatan dan persepsi pengetahuan, (OR_1 = 4,82 (95% CI = 1,26 -18,34) dan OR_2 = 1,18 (95% CI = 0,2 - 6,98)). Faktor yang paling dominan adalah tingkat pendidikan (PAR% = 38,8%).

Kata kunci: Kusta, *perceived* stigma, Sitanala

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Introduction

Leprosy is one of neglected tropical diseases (NTDs), and still considered serious health problems.[1] The problems are not only health problems, but also social, economy, culture, security and national defense.[2] In addition, leprosy is one of the NTDs included in Strategy Research Implementation/ Operation Control on Malaria, Tuberculosis, and NTDs in Indonesia, 2016-2019.[3] Despite Indonesia is an endemic country for tropical infectious diseases, there are differences in distribution of diseases that require strategies which match with the specific problems in each region to be able to achieve eradication or elimination targets of tropical infectious diseases like leprosy.

Leprosy is a chronic disease caused by *Mycobacterium leprae*.[4] The disease mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes.[4] Leprosy is transmitted via droplets, from person to person, from the nose and mouth, during close and frequent contacts with untreated cases. There is no vector involved in the transmission.[2,4,5]

According World Health Organization (WHO) report in 14 countries, Indonesia still ranks the third in the world after India and Brazil for new leprosy cases detection. These 14 countries represent 95% of the global leprosy burden. Globally, by 2015 Indonesia reported 17,202 cases (8.16%), Brazil 26,395 cases (12.52%), and India 127,326 cases (60.41%).[6] The number of cases has decreased compared to the previous year, but people affected by leprosy still get social impact.

Banten Province is one of provinces in Indonesia that has not been included in the list of provinces that have achieved elimination of leprosy.[7] In addition, Banten Province had high leprosy cases, with 818 cases of newly registered patients in 2012 (Paucibacillary leprosy and 679 cases Multibacillary leprosy. The new case detection rate (NCDR) was 7.38 per 100,000 population and the proportion of Multibacillary cases was 83%. The rate of disability level 2 by 9.8% (80 cases) and cases in children aged less than 15 years of 13.7% (112 cases).[8] There is a colonization or leprosy village located in Sitanala, Tangerang District, Banten Province. There is a hospital in area of leprosy village. Not only for treatment, but this hospital also serves as a medical rehabilitation center for leprosy, social rehabilitation, and rehabilitation for work.

Leprosy develops slowly which can cause severe dysfunction and destruction that cause disability to the people affected by leprosy.[5,6] A study conducted in the Nganget Village, Tuban District, found that 38.2% of respondents did not have proper self-care, 64.8% had leprosy type and almost half of respondents had experienced grade 2 defect (88.7%).[9] Impairments and disability cause stigma and discrimination among the people affected.[5,10] There are three kinds of stigma related to leprosy, namely experienced stigma, perceived stigma, and self-stigma. Experienced stigma is the stigma that a person gets from a society, such as being discharged from work, school, divorce, being denied in access to public transportation, getting discriminated, etc. Self-stigma is a person's feelings towards themselves that keeps them away from society that ultimately gets stigmatized. Perceived stigma is the perception, expectation, or fear, or concern of discrimination and awareness of negative attitudes that society will do to itself if a person experiences a certain condition.[11]

Perceived stigma will cause people who suffer fromleprosy to lose their productivity. In addition, perceived stigma will make them poor, and being a beggar to survive. Stigma was the main determinant of social participation, and therefore disability.[12] The consequences of stigma can be seen from the psychosocial dysfunction to isolation, rejection and participation restriction.[13] Social destruction due to several conditions including stigma, discrimination, poverty, disability and loss of freedom are still major obstacles to be overcome by people affected by leprosy, professional and health programs.[14]

Factors related to perceived stigma were nondisclosure, self-esteem and concealment.[15] A study conducted in Western Nepal found that median score of perceived stigma was 10 (ranged from 0–34). In addition, a study conducted in Western Nepal found that illiterate persons perceived economical inadequacy as theychanged their occupation due to leprosy; patients who lacked information on leprosy, the causes and transmission of leprosy, had deformities; ulcers and odorous ulcer, and those who had perception of leprosy as a severe disease and difficult to treat had higher perceived stigma score.[15] In India, a study using the The Explanatory Model Interview Catalogue (EMIC) scale found that perceived stigma was 97% consisting of 16% severe perceived stigma, 37% moderate perceived stigma, and 44% mild perceived stigma.[16]

In Indonesia, leprosy is still stigmatized disease and stigma remains a serious problem. Based on the results of preliminary study at Technical Implementation Unit of Rehabilitation for Ex-Leprosy in Nganget Village, Singgahan Subdistrict, Tuban District, Indonesia, 55.9% of respondents had negative perceived stigma. In addition, study conducted in five regions in Indonesia found that around 60% of people reported activity limitations and participation restrictions and 36% anticipated stigma.[12]

Thus, study was intended to identify the most dominant variables from respondent characteristics (age, sex, education level, employment status, marital status), disease characteristics (type of leprosy, reaction of leprosy, level of disability), perception of knowledge, basic of knowledge, social participation, and cultural values that

related to perceived stigma.

The study on perceived stigma refers to rethinking theoretical approaches to stigma, including a Framework Integrating Normative Influences on Stigma (FINIS), Health Belief Models, and the theory of Health Education Planning.[17-19] Perceived stigma is measured using the Explanatory Model Interview Catalog (EMIC).[11] This study aimed to determine the most dominant factor which might relate to perceived stigma in people affected by leprosy in leprosy village of Sitanala, Tangerang District, Indonesia.

Method

The data used was secondary data from cross-sectional survey of a thesis that aimed to determine factors related to perceived stigma of leprosy in leprosy village of Sitanala, Tangerang District, Indonesia on December 2013.[20] The original cross-sectional survey was conducted on 304 people affected by leprosy by purposive sampling. The variables were respondent characteristics (age, sex, education level, employment status, marital status), disease characteristics (type of leprosy, reaction of leprosy, level of disability), perception of knowledge, basic of knowledge, social participation, and cultural value.

The perceived stigma variable was measured by the EMIC scale questionnaire. This instrument has been recommended by The International Federation of Anti-Leprosy Association (ILEP) to measure perceived stigma in people affected by leprosy. The EMIC scale consists of 13 questions that cover several aspects of leprosy. Each question has four possible answers, namely "strongly agree", "agree", "less agree" and "disagree". Sequentially, each answer has a score of 3, 2, 1, 0. In this study, the cut of point scale used for EMIC was median value, meaning that there was a higher stigma in people affected by leprosy if the total EMIC score was median.

Perception of knowledge is the view of respondents associated with leprosy-related beliefs and myths in society such as the transmission, causes, impacts and others. This statement consists of 10 questions. Scores for the answers of each statement are strongly agree = 3, agree = 2, less agree = 1, disagree = 0. In this study, the cut of point scale used for perception of knowledge was median value, meaning that the higher score of perception of knowledge would support people affected by leprosy to have negative perception of knowledge.

Basic knowledge of leprosy is the basic information or knowledge about leprosy that includes the causes of leprosy, the type of leprosy that is contagious, and the transmission of the disease. This question consists of five questions. Respondents would get value 1 if they answered correctly and get 0 if they answered incorrectly. The cut of point scale used for basic knowledge was mean value, meaning that the higher score of knowledge would support respondents to have good knowledge related to leprosy.

Cultural value is the respondent's perception of the prevailing cultural values in the society regarding leprosy. The score for the cultural value statement is strongly agree 3, agree = 2, less agree = 1, disagree = 0. In this study, the cut of point scale used for cultural value was median value, meaning that there was a higher cultural value would support a greater percentage of people affected by leprosy to get perceived stigma.

Demographic variables, social characteristics, and disease characteristics that include age, sex, education, level occupation, marital status, type of leprosy, disability level, and leprosy reactions were asked directly to the respondents. Univariate analysis was used to see distribution and frequency variables. Chi-square test and independent T-test were applied to determine the relation of independent variables and dependent variable with alpha 5%. Multivariate logistic regression analysis was used to determine the dominant factor related to perceived stigma.

Results

Leprosy village of Sitanala, Tangerang District is inhabited by hundreds of people who have experienced leprosy and healthy society. This study aimed to determine the most dominant factor which might relate to perceived stigma in people affected by leprosy. This study only focused on people affected by leprosy living in the region. Total of respondents was 304 respondents. This study got assistance from research assistants and community leaders in the area.

Based on Table 1, the mean of respondents was 50.62 years with 95% confidence level between 49.31 to 51.93 years. The youngest age was 24 years old and the oldest

Table 1. Distribution of Respondents' Age

Variable	Minimum-Maximum	Varian	SD	Median	Mean	95% CI	
						Lower	Upper
Age	24-97	134.88	11.61	50	50.62	49.31	51.93

Notes:
SD= Standar Deviation; CI= Convidence Interval

Table 2. Distribution of Univariate Variables in Rehabilitation of Leprosy in Sitanala

Variables	Category	Frequency	Percentage (%)
Sex	Female	127	41.8
	Male	177	58.2
Education	No education	48	15.8
	Primary education	233	76.6
	Secondary education	23	7.6
Occupation	Unemployed	145	47.7
	Farmer	8	2.6
	Entrepreneur	45	14.8
	Private employees	41	13.5
	Civil servants	8	2.6
	Janitor	36	11.8
	Others	21	6.9
Marital status	Married	261	85.9
	Single	3	1
	Divorced	4	1.3
	Widow/widower	36	11.8
Type of leprosy	Multibacillary	144	47.4
	Paucibacillary	160	52.6
Reaction of leprosy	Yes	217	71.4
	Never	87	28.6
Level of disability	Level 2	212	69.7
	Level 1	41	13.5
	Level 0	51	16.8
Perceived stigma	Negative	153	50.4
	Positive	151	497
Perception of knowledge	Negative	153	50.3
	Positive	151	49.7
Basic of knowledge	Poor	141	46.4
	Good	163	53.6
Social participation	Lower	128	42.1
	Higher	176	57.9
Cultural values	Negative	172	56.6
	Positive	132	43.4

Table 3. Age Related to Perceived Stigma in Rehabilitation of Leprosy in Sitanala

Variable	Perceived Stigma	n	Mean	Standard Deviation	Standard Error	p Value	95% CI	
							Lower	Upper
Age	Older	153	50.50	10.91	0.88	0.851	-2.88	2.37
	Young	151	50.75	12.32	1.00			

Notes:
n = Number of Sample; CI= Confidence Interval

was 97 years old.

Based on Table 2, most of respondents were males (58.2%), low educated (92.4%), unemployed (47.7%), and married (85.9%). In addition, approximately 52.6% of respondents had Multibacillary leprosy type and 71.4% of respondents had experienced leprosy reactions. Most respondents had experienced disability level 2 (69.7%).

There were 50.4% of respondents with high perceived stigma (negative), 50.3% of respondents had negative perception of knowledge, 56.6% of respondent's cultural environment supports a person to have negative perceived stigma. However, there were 53.6% of respondents with a good knowledge of leprosy and 57.9% of respondents with high social participation.

Based on Table 3, the mean age of respondents with negative perceived stigma was 50.50 years with a standard deviation of 10.91. Meanwhile, the mean age of respondents with positive perceived stigma was 50.75 years with a standard deviation of 12.32. There was no significant relation between age and perceived stigma.

Based on Table 4, uneducated respondents had 1.92 times greater risk of having negative perceived stigma compared to respondents with secondary education (PR= 1.92; 95% CI = 1-3.72). Respondents with negative perception of knowledge had 1.66 times greater risk of having negative perceived stigma compared to respondents with positive perception of knowledge (PR = 1.66; 95%

Table 4. Factors Related to Perceived Stigma in Rehabilitation of Leprosy

Variables	Category	Perceived Stigma				p Value	PR (95% CI)
		Negative		Positive			
		n	%	n	%		
Sex	Female	64	50.4	63	49.6	0.985	1.00 (0.8-1.26)
	Male	89	50.3	88	49.7		
Education	No education	28	58,3	20	41.7	0.025	1.92(1-3.72)
	Primary education	118	50.6	115	49.4	0.064	1.66(0.89-3.13)
	Secondary education	7	30.4	16	69.6		1
Occupation	No	72	49.7	73	50.3	0.820	0.98(0.78-1.22)
	Yes	81	50.9	78	49.1		
Marital Status	Single	23	53.5	20	46.5	0.670	1.07(0.79-1.46)
	Married	130	49.8	131	50.2		
Perception of knowledge	Negative	96	62.7	57	37.3	<0.0001	1.66(1.31-2.11)
	Positive	57	37.7	94	62.3		
Type of leprosy	PB	86	53.8	74	46.2	0.210	1.16(0.92-1.45)
	MB	67	46.5	77	53.5		
Reaction of leprosy	Yes	106	48.8	111	51.2	0.420	0.9(0.71-1.15)
	No	47	54	40	46		
Level of disability	Level 2	112	52.8	100	47.2	0.080	1.35(0.94-1.94)
	Level 1	21	51.2	20	48.8	0.250	1.31(0.83-2.51)
	Level 0	20	39.2	31	60.8		1
Basic of knowledge	Poor	69	48.9	72	51.1	0.650	0.95(0.76-1.19)
	Good	84	51.5	79	48.5		
Social participation	Lower	75	58.6	53	41.4	0.010	1.32(1.06-1.65)
	Higher	78	44.3	98	55,7		
Cultural value	Negative	110	64	62	36	<0.0001	1.96(1.5-2.57)
	Positive	43	32.6	89	67.4		

Notes:
n = Number of Sample; PR= Prevalence Ratio; CI= Confidence Interval

Table 5. Dominant Factor Related to Perceived Stigma in Rehabilitation of Leprosy

Model	β	SE	p Value	OR	PAR %	95% CI	
						Lower	Upper
Perception of knowledge	-0.31	0.61	0.613	0.74	24	0.22	2.42
Secondary education	Ref		0.113				
Primary education	0.91	0.52	0.080	2.47	38.8	0.90	6.82
No education	1.24	0.59	0.037	3.45	38.8	1.08	11.06
Level 0	Ref		0.760				
Level 1	0.21	0.69	0.768	1.23	13.3	0.33	4.77
Level 2	-0.2	0.48	0.685	0.82	22	0.32	2.11
Cultural value	1.21	0.26	0.000	3.36	34	2.02	5.61
Perception of knowledge * level of disability 0	Ref		0.025	0.03			
Perception of knowledge * level of disability 1	0.17	0.91	0.855	1.18	-	0.20	6.98
Perception of knowledge * level of disability 2	1.57	0.68	0.021	4.82	-	1.26	18.38
Constant	-1.84	0.63	0.003	0.16			

Notes:
SE= Standard Error; PAR= Population Attributable Risk; OR= Odds Ratio; CI= Confidence Interval

CI = 1.32-2.11). Respondents with lower social participation had 1.32 timed greater risk of having negative perceived stigma compared to respondent with higher social participation (PR = 1.32; 95% CI = 1.06-1.65). Respondents with negative perception of cultural values had 1.96 times greater risk of having negative perceived stigma compared to respondents with positive perception of cultural value (PR = 1.96; 95% CI=1.5-2.57).

Based on Table 5, factors related to perceived level stigma were perception of knowledge, education, level of disability, cultural value. In respondents with level 2 of disability compared to respondents with level 0 of disability, respondents with negative perception of knowledge had 4.82 times greater risk of having negative perceived stigma compared to respondents with positive perception of knowledge (OR = 4.82; 95% CI = 1.26-18.38). In respondents with level 1 of disability compared to respondents with level 0 of disability, respon-

dents with negative perception of knowledge had 1.18 times greater risk of having negative perceived stigma compared to respondents with positive perception of knowledge (OR = 1.18; 95% CI = 0.2-6.98).

Respondents with negative perception of cultural value had 3.36 times greater risk of having negative perceived stigma compared to respondents with positive perception of cultural value (OR = 3.36; 95% CI = 2.02-5.61). Uneducated respondents had 3.45 times greater risk of having negative perceived stigma compared to respondents with secondary education (OR = 3.45; 95% CI = 1.08-11.06). In addition, respondents with primary education had 2.47 times greater risk of having negative perceived stigma compared to respondents with secondary education (OR = 2.47; 95% CI = 0.9-6.82).

The largest population attributable risk percent was the education level 38.8%. It means that the risk of perceived stigma could be prevented if respondents had high level of education. Thus, the dominant factor related to perceived stigma was education level.

Discussion

This study was intended to identify factors and the most dominant variable from respondent characteristics (age, sex, education level, occupation, marital status), disease characteristics (type of leprosy, reaction of leprosy, level of disability), perception of knowledge, basic of knowledge, social participation, and cultural value that influenced to perceived stigma. This study found that factors related to perceived stigma at Rehabilitation of Leprosy in Sitanala were perception of knowledge, level of education, cultural value, and social participation. Sex, occupation, marital status, type of leprosy, reaction of leprosy, and basic of knowledge had no significant relation to perceived stigma. In multivariate logistic regression analysis, factors related to perceived stigma were education level and cultural value. In addition, there was a modified effect between the perception of knowledge with the level of disability. The most dominant factor related to perceived stigma was level education.

Based on the analysis results, there was a significant relation between education level and perceived stigma. The proportion of uneducated respondents had a higher perceived stigma than respondents who had primary and secondary education. A systematic review found that low education had association with stigma.[13] This is because the educated respondents have better information and thinking than the uneducated respondents. In addition, the educated people have more life experiences than the uneducated. Therefore, it can affect their way of thinking. Formal education is basically a process to the intellectual maturity. Education cannot be separated from the learning process. Learning process is essentially a refinement of the potential or ability on the biological and psychological organism that is needed in the human relationship with the community. Education is an effort or activity to create conducive community behavior.[21] Education is related to someone's reading ability. The higher perceived stigma score was found in illiterate person.[15] In addition, low education and economic status, older age groups and disabilities enhance both perceived and enacted stigma. However, in older patients, low education and with deformity revealed the highest stigma.[22]

There are various factors which construct the perception of stigma in people affected by leprosy, such as knowledge of leprosy. In this study, perception of knowledge related to perceived stigma. This finding is in line with study in Western Nepal stating that patients who had perceptions that leprosy disease was difficult to treat and a severe disease had higher perceived stigma compared to those who did not.[15] From historical aspect, knowledge of leprosy pathophysiology and stigma will affect the lives of people affected by leprosy. Stigma generally occurs because it refers to people's fear of people with leprosy. This happens due to the lack of knowledge and suspiciousness of disease.[23]

Physical disorder causes people affected by leprosy have difficulty in doing their activities. Disability in people affected by leprosy makes them more prone to get perceived stigma. In this study showed that type of disability related to perceived stigma. The associated visible deformities and disabilities have contributed to the stigma and discrimination experienced by people affected by leprosy, even among those who have been cured.[24] Visible deformities and disabilities have been found to be the prominent contributor of stigma development in people affected by leprosy which have an adverse effect on quality of life.[25] Physical disability will reduce the self-esteem and confidence of people suffering from leprosy, so they will stay away from the social environment and this condition evokes stigma.[26] A study conducted in Western Nepal showed that respondents with deformities and ulcers had higher perceived stigma score.[15]

The cultural beliefs and misconceptions on the causes and transmission of leprosy can make perceived stigma. In this study showed that cultural beliefs had related to perceived stigma. A study reported that the cause of stigma were cultural and religious beliefs.[10] Self-perception of prejudice and stigma depends on each individual who is adapted to a pattern of social behavior.[27] People believe that leprosy is caused by the wrath of God for committed sins, disturbing jinn, heredity, the curse of an angered father, the breaking of food, and a person could be infected through body fluids such as blood, urine, genital fluid, and pus.[28] In culture, a person is judged by the ability to bear life and unemployment because leprosy can be a lasting effect not only economically, but also psychosocially.[29]

Based on the analysis results, there was a significant relation between social participation and perceived stigma. This is because people who are active in social activities have experience and a better outlook than respondents who are less active in social activities. Social participation had been the focus of disease studies that historically discriminated and excluded people from social interactions such as leprosy cases.[14] Self-rejection due to aesthetics problems would cause the person to avoid social participation and cause social rejection.[2] The severity of community stigma is correlated with the severity of participation restrictions.[12]

This study found that there was no significant relation between respondents who worked and who did not work on perceived stigma. This can be due to the distribution of respondents who work and do not work evenly at all levels. Socioeconomic status can be seen based on the level of work and the income of a person. The socioeconomic level will affect the level of education and knowledge of a person so as to influence the views and ways of thinking.[21] A study found that respondents with inadequate had higher perceived stigma score with p value = 0.014.[15] In addition, higher perceived score was found in respondents who had changed their occupation due to leprosy (p value = 0.018).[15] Stigma, shame and problems related to difficulties in employment were most frequently reported cases.[12]

The results of analysis found that sex and perceived stigma had no significant relation. Characteristics, traits, and disorders experienced by respondents were almost the same in both sexes. Most respondents received information related to leprosy after they were hospitalized. In addition, the psychological development between men and women were equal in the village. Another study found that women hide their disease and experience some social problems.[30] Thilakavathi *et al.,*[31] found 4 out of 22 women after being diagnosed with fear, worries about stigma compared 0 of 9 men. Several studies found a higher percentage of women experiencing stigma and only one article indicated a higher perceived stigma in men compared to women, in society and in social institutions.[32] Stigma affects all leprosy patients, women suffer more adversely.[30]

This study obtained no significant differences in married and unmarried respondents with perceived stigma. They got married generally with their fellow patients after being diagnosed with leprosy, so their views and feelings were similarly related to leprosy with single respondents. In addition, after the respondent was declared leprosy by the doctor, their wife or husband divorced them, so they did not get the support system from their partner. Stigma and problems related to marriage were the most frequently reported problem.[12]

In this study, no significant relation was found between basic knowledge of respondent and perceived stigma. This finding had not been consistent with study in Western Nepal in which patients who obtained less information on leprosy (p value < 0.0001) and knowledge of leprosy cause (p value < 0.0001) had higher perceived stigma compared to those who did not.[15] Lack of accurate knowledge of leprosy in the community can be an important factor in inhibiting leprosy elimination.[33]

This study found that type of leprosy did not relate to perceived stigma. The study result was not in line with a study in Brazil that the prejudice and stigma associated with the lesions and more visible in Multibacillary leprosy and result in the worsening of the social aspects.[27] No significant association was found in the leprosy reaction with perceived stigma. Leprosy reaction is one of the causes of acute damage to nerve function and disability.[2] In addition, this leprosy reaction also relates to the type of leprosy.

In the study, there was a modified effect between the perceptual of knowledge with the level of disability in relation to perceived stigma. The relation between perception of knowledge with perceived stigma was modified by level of disability. In respondents who had a disability level 2 and a negative perception of knowledge would have a higher perceived stigma risk. This was due to self-rejection related to aesthetics.[14] In addition, if people affected by leprosy had a visible disability and negative perception of knowledge, they would find it difficult to adapt to their family.[10,15] Some people with leprosy may have a distinctive odor caused by an infected ulcer.[10] Shame, worry, fear, and problems related to disability will make people affected by leprosy alienated. The negative perception of leprosy will also lead them to self-isolation resulting in stigma. Not only does this stigma come from them, but it will also appear from the community.

Based on the result, it is essential to expand the current knowledge of leprosy. In addition, the intervention model should be more focused on addressing perceived stigma. Physical, social and economic rehabilitations are also indispensable for people affected by leprosy because the rehabilitation can restore their self-esteem and status in maintaining their quality of life and productivity

Conclusion

Factors related to perceived stigma are perception of knowledge, level education, level disability, cultural value and social participation. The dominant factor related to perceived stigma is level education. In addition, there is a modified effect between the perceptual of knowledge with the level of disability. Therefore, it is necessary for intervention, counseling to factors related to perceived stigma about the leprosy so as to decrease the perceived stigma, especially how to elevate their knowledge of leprosy disease.

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