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The influence of stigma and depression on quality of life of leprosy patients

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ABSTRACT

Jenny MC Siagian, Carla R Marchira, Agnes S Siswati - ***The influence of stigma and depression on quality of life of leprosy patients***

Background: Stigma attached to leprosy-affected individuals is one of the strongest stigma of diseases. Depression is often occurred to many lepers. Stigma and depression are two factors which affect the quality of life of the lepers.
Objective: To determine whether stigma and depression affect the quality of life of leprosy patients in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital.
Methods: It was a quantitative and cross-sectional research. The quantitative analysis was conducted with chi-square and multiple regression methods.
Result: There was no significant correlation between stigma and quality of life of leprosy patients. The factors which significantly correlated with quality of life were gender, income, and depression score ($p < 0.05$). Depression score significantly affected the quality of life (B 1.876; $p < 0.05$; CI 1.166-36.566).
Conclusion: Depression affected the quality of life more than deformity and demographic factors among leprosy patients in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Yogyakarta.

Key words: stigma - depression - leprosy - quality of life

ABSTRAK

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Latar belakang: Stigma yang melekat terhadap penyakit lepra merupakan salah satu stigma penyakit yang kuat. Gangguan depresi juga seringkali dialami oleh penderita lepra. Stigma dan depresi merupakan faktor-faktor yang mempengaruhi kualitas hidup penderita lepra.
Tujuan: Untuk mengetahui apakah stigma dan depresi berpengaruh lebih besar terhadap kualitas hidup dibanding faktor-faktor lain pada penderita lepra di poliklinik kulit dan kelamin RSUP DR Sardjito Yogyakarta.
Metode: Penelitian ini adalah penelitian kuantitatif dan bersifat *cross sectional*. Analisis kuantitatif bersifat deskriptif-analitik dengan menggunakan metode kai kuadrat dan regresi berganda.
Hasil: Tidak didapatkan korelasi bermakna antara stigma dan kualitas hidup penderita lepra. Faktor-faktor yang memiliki korelasi bermakna dengan kualitas hidup adalah jenis kelamin, tingkat penghasilan, dan skor depresi ($p<0,05$). Dari analisis multivariat didapatkan bahwa skor depresi berpengaruh bermakna terhadap kualitas hidup (B 1,876; $p<0,05$; CI 1,166-36,566).
Simpulan: Depresi mempunyai pengaruh lebih besar terhadap penurunan kualitas hidup penderita lepra di poliklinik kulit dan kelamin RSUP DR Sardjito Yogyakarta dibandingkan kecacatan dan faktor-faktor demografik.

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INTRODUCTION

In sociology context, stigma is a phenomenon where someone with a certain attribute is rejected or discredited by surrounding society because of the attribute he/she has. This attribute may be a behavior conflicted with the society norm, an unusual or different ethnic or sexual preference, or physical attribute that differentiated him/her from other people. Diseases tend to bring stigma to its patients are chronic diseases, communicable diseases, diseases causing visible deformity on his/her body, or mental disorders. Patients of those diseases are often avoided by surrounding people or treated differently in the society. Epilepsy, TBC, HIV/AIDS, psoriasis, and schizophrenia are several examples of those diseases. Stigma related to leprosy is one of the stronge disease stigma. Even the word leprosy can be associated with stigma.[1,2,3,4,5,6,7] Leprosy is one of the oldest diseases in the world. It has been known since 1400 BC in several oldest civilizations in China, India, and Egypt.[8,9] Stigma attached to patients of leprosy has been started since long time ago, that is, since leprosy pandemy in Europe around 1000-1500 BC.[10] At that time, patients of leprosy were treated as exiles because of their visible deformities and disabilities.[11,12] The society observed leprosy as incurable communicable disease, and as a frightening disease related to society cultural belief. In India, China, Africa, and in the society of Moslems and Christians, leprosy has been considered as God's penalty for the sins or moral infringement, or caused by black magic curse. For most of the patients of leprosy, stigma is the heaviest burden of contracting the disease.[9,12,13]

It is estimated that around 10-15 million world population suffer from leprosy, mostly in developing countries in tropic and subtropic countries. This disease is endemic in most areas in Asia, particularly in India, Sahara in Africa, Middle and South America, Pacific islands, and Philippinnes.[14] The high number of patients with leprosy and the emergence of new cases had brought heavy economic and health burden in many developing countries.[10] Based on WHO data, in 9 countries of Asia, Africa, and Latin America, leprosy is still considered as publich health problem[9]. Disease burden in those 9 countries is estimated to be 75% of global disease burden.

There were 0.98 patient of leprosy per 10000 people in Indonesia until December 2005. Daerah Istimewa Yogyakarta, along with Central Java and West Java, has prevalence of leprosy under 1 per 10000 people, therefore, those areas are categorized as low-endemic leprosy areas. Although national leprosy elimination level has been achieved in 2000, there are still some areas in Indonesia that have quite high number of leprosy patients, such as in Papua, Maluku, North and South Sulawesi, with prevalence more than 3 per 10000 people.[15]

Patients of leprosy in Indonesia still feel the stigma from surrounding community. Suryanda in his research in Prabumulih, South Sumatera, supported the fact that stigma against leprosy was still large in the community.[16] It was mentioned that most patients or ex-patients of leprosy and community still considered leprosy as a very dangerous communicable disease, inherited disease, "sent" disease, or caused by past mistakes. The society is scared and disgusted of patients of leprosy who had physical deformities. The patients themselves are not comfortable to be told about their disease and choose to hide that they suffer from leprosy.

In Joseph & Rao study, it was found that deformity caused by leprosy resulted in a limitation in the patients' activity, therefore, their quality of life were decreased.[17] The decrease in quality of life in leprosy patients was also confirmed in a study by Tsutsumi *et al.*[18] The result suggested that leprosy patients had lower total scores of quality of life compared to general population, including physical and psychological quality of life. In this Bangladesh study, leprosy female patients were spared from this social stigma, because they wore headdresses, robes, and seldom went out of their houses. Nevertheless, they did not spare from self-stigma, because leprosy decreased their self-image, and their families knew that they had leprosy.

Those results were supported by Wong & Subramaniam.[13] In their article, it was suggested that leprosy was often suffered by patients in their productive age and its chronic characteristic limited patients to work and to have roles in the society. Visible disability and deformity caused a decrease in their self-esteem. In a whole, leprosy decreased the patient's quality of life.

Studies from time to time showed that there was an increase in the prevalence of mental disorders in leprosy patients, and mental health of leprosy pateints was generally worse than general population.[19,20,21,22,23,24] The high number of patients who affected mentally was not the direct effect of leprosy, but it was caused more by social rejection that they experienced.[12]

Several studies showed that most mental disorders experienced by leprosy patients was depression.[20,23,24] In the study in Bangladesh, Tsutsumi *et al.* found that leprosy patients were inclined to be depressed than general population.[23] It was also found that 87.9% of patients felt isolated from their families, 67.% feels isolated from their relatives and friends, 68.5% felt isolated from the society, and 85% were felt hurt from negative behavior towards them because they had leprosy.[23]

This study was conducted in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital, the referral hospital for investigation and treatment of leprosy in Daerah Istimewa Yogyakarta and its surroundings. Investigation and treatment program applied was according to Multi Drugs Therapy program by WHO. Data of leprosy patient visits in June 2008 showed that there were 53 patients of leprosy. During 2007, leprosy was always included in the top 6 diseases in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital, with average visits of 74 patients per month, and total new cases was a minimum of 1 and a maximum of 8 per month. It showed that although Daerah Istimewa Yogyakarta and Central Java are areas with low-endemic leprosy, new cases are still found.[25,26]

This study was aimed to investigate the effect size of stigma and depression on quality of life of leprosy patients in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital.

METHODS

Design of the study was observations study. Subjects of this study were leprosy patients in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital. Samples were taken with consecutive sampling, where subjects who attended to the Outpatient Clinic and satisfied the inclusion criteria were included in this study, until the total number of the subjects achieved the needed number of samples. From total samples included, a purposive sampling was conducted to achieve the total number of subjects who would be interviewed. The estimation of minimum sample size needed in quantitative study used single sample size formula, using correlation coefficient. The minimun sample size needed was 31 patients.[27] Respondents in this study were 35 patients. The study was conducted in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital, from August to September 2008.

Instruments used in this study were personal data questionnaire, Stigma Items instrument, Beck Depression Inventory (BDI), family social support instrument with Likert scale, and quality of life instrument SQLI.

Before the analysis was conducted, the validity and reliability tests were conducted on Stigma Items dan Beck Depression Inventory, using Pearson correlation and a-Cronbach tests. Chi-square analysis was conducted to assess the relationship between each risk factor with quality of life. To observe the degree of relationship of the variables, Spearman test was used. Logistic regression test was conducted to find out the the effect size of the significant risk factors on the quality of life.

RESULT AND DISCUSSION

Characteristics of research subjects

Subjects were 35 patients of leprosy, consisted of 28 (80%) males and 7 (20%) females. Average age of the subjects was 34.11±15.20 years old, with the youngest subject was 10 years old and the oldest was 69 years old. The patients mostly (16 patients/ 45.7%) had basic educational level, consisted of elementary school and junior high school. The income of the subjects mostly less than Rp 547.000,- (54.3%), and they were mostly married (54.3%). From all subjects, there were 8 subjects (22.9%) who had visible deformity. The average of stigma scores was 7.43±6.19, the lowest score was 0 and the highest was 25. The average of family social support scores was 46.97±8.76, the lowest score was 23 and the highest was 57. The average of depression scores was 12.31±10.37, the lowest score was 1 and the highest was 37. The average of the score of quality of life was 13.89±2.00, the lowest score was 9 and the highest was 16. Meanwhile, the median of instruments used for statistical analysis were 6 for stigma score, 50 for of family social support score, 11 for depression score, and 14 for quality of life score. The complete characteristics of subjects are shown in the following table.

TABLE 1. The characteristics of research subjects

Variab les	Total number (%)	Average ± SD	CI (95%)
Gender		-	-
-Male	28 (80.0)		
-Female	7 (20.0)		
Age	-	34.11 ± 15.20	28.89 – 39.34
Marital status		-	-
-Single	16 (45.7)		
-Married	19 (54.3)		
Educational level		-	-
-SD/MI/SMP/MTs	16 (45.7)		
-SMA/SMK/MA/MAK	12 (34.3)		
-Diploma/S1/Doctor	7 (20.0)		
Income per month		-	-
-<Rp 547.000,-	19 (54.3)		
->Rp 547.000,-	16 (45.7)		
Deformity		-	-
-Visible	8 (22.9)		
-Not visible	27 (77.1)		
Stigma Score		7.43 ± 6.19	5.30 – 9.56
Stigma			
-No stigma	2 (5.7)		
-Mild	17 (48.7)		
-Severe	16 (45.6)		
Family social support score		46.97 ± 8.75	43.97 – 49.98
Family support			
-Poor	3 (8.6)		
-Moderate	9 (25.8)		
-Good	23 (65.6)		
Depression Score		12.31 ± 10.37	8.75 – 15.88
Depression			
-Normal	17 (48.7)		
-Mild	9 (25.8)		
-Moderate	6 (16.9)		
-Severet	3 (8.6)		
Quality of Life Score		13.89 ± 2.00	13.20 – 14.57
Quality of life			
-Poor	0		
-Moderate	4 (11.5)		
-Good	31 (88.5)		

In this study, 80% samples were males and 20% were females. The ratio of male and female leprosy patients generally was 2-3:1.[11,14] In this study, the ratio was 4:1, almost similar to the general ratio. The difference may be caused by the different sample size.

The average age was 34 years old, with the youngest subject was 10 years old and the oldest was 69 years old. This is consistent with the references that suggested that leprosy might be suffered by any age and leprosy mostly suffered by those in productive age.[13,14]

The subjects mostly (47.7%) had basic educational level, consisted of elementary school and junior high school. The study by Tsutsumi *et al.* and Withington *et al.* showed that the majority of leprosy patients were not educated.[23,28] Tsutsumi *et al.* suggested further that the second most educational level (27.1%) of the patients was basic education.[23]

Explanation on why there were leprosy patients who had lower educational level or not educated might be related to their income. It has been known that leprosy mostly occurred in third world countries, where most of the people are poor. In a study by Duarte *et al.* in Brazil, it showed that there were up to 92% leprosy patients who had under-average income.[29] In this study, the result was similar, where majority (54.3%) of income level was under regional minimum wage (Rp 547.000,-).

The majority (54.3%) of the subjects in this study were married. This is comparable to the result of a study by Setyawati, but contradicted with the result of a study by Nisar *et al.* in Pakistan who suggested that suffering from leprosy would made the patients difficult to get maried.[30,31] In this study, it was assumed that the subjects had been married before they were diagnosed to have leprosy.

There were 22.9% subjects with visible deformity, consisted of contracture of fingers, atrophy, and drooping eyelid. There were many subjects who had hyperpigmentation on the face and body skin, caused by Lamprene treatment.

In the terms of family social support, most subjects had good family support scores (65.6%). There were 25.8% subjects who had moderate scores, and only 3 subjects (8.6%) who had poor family support scores. Most subjects had good family social support, and it might be caused by close familial and community culture in south Asia, including in Indonesia.[12]

There were 88.5% subjects who had good quality of life scores. This is comparable with the result by Setyawati that most subjects had a good quality of life score.[30] It might be caused by the measurement which conducted in this recent week.

With median stigma score of 6, there were 16 subjects (45.6%) who had high stigma score and 17 subjects who had low stigma score (48.7%). There were 2 subjects (5.7%) who had score 0, which meant that he/she had not suffered from stigma. These result showed that almost all subjects (94.3%) had a minimum of one subjective stigma experience. This is might be caused by negative self-esteem in leprosy patients, although they did not suffer from social stigma from the society.

There were more than half subjects (51.3%) who had depression symptoms, consisted of 9 subjects (25.8%) who had mild depression score, 6 subjects (16.9%) who had moderate depression score, and 3 subjects (8.5%) who had severe depression score. This is similar with the result of previous studies, that suggested that depression was a mental disorder who were suffered by many leprosy patients.[20,23,24]

Bivariate analysis

The result of bivariate analysis showed that only gender ($x^2 = 4.833$; $p < 0.05$), income ($x^2 = 4.804$; $p < 0.05$), and depression score ($x^2 = 6.415$; $p < 0.05$) who had significant correlation with quality of life. Level of corelation between gender factor and quality of life, and between income and quality of life, was weak ($r = 0.372$ and $r = 0.370$, respectively). Depression score was moderately correlated with quality of life ($r = 0.428$).

From the calculation of prevalence ratio (PR), the PR for gender was 9.273 (CI 0.979-87.868). Gender factor showed PR > 1, but the Confidence Interval (CI) was went across the value of 1, which meant that gender factor was not a risk factor of quality of life. Value of PR for income was 4.767 (CI 1.137-19.977), and PR value of depression score was 6.240 (CI 1.439-27.059). From the results, the risk factors of quality of life were income and depression score.

Further, it was found that being male was a protective or preventive factor for a high quality of life score (PR = 0.458, CI 0.264-0.795), or in the contrary, male patients had a higher risk to had a low quality of life score compared to female patients. There were more male subjects in this study who had lower quality of life score compared to female patients. This is similar with the result of a study by Joseph & Rao who suggested that male leprosy patients had lower quality of life score compared to female patients.[17] In Joseph & Rao study, it was assumed that in India, women were the second class in the society, who were less appreciated compared to men.[17]

Bivariate analysis also showed that income was significantly related to quality of life. This is similar with the result of study by Joseph & Rao and Tsutsumi *et al.*[17,18] Subjects with income < Rp 547.000,- per month was a preventive factor for high quality of life score (PR 0.459, CI 0.219-0.962). In other words, subjects with income < Rp 547.000,- per month had higher risk to had lower quality of life score compared to subjects with income > Rp 547.000,- per month. Materials are one of the components of quality of life, therefore, it was natural that the income level is related to individual quality of life.[32]

Bivariate analysis showed that depression score was a risk factor of quality of life. The higher the depression score, the lower the quality of life score of leprosy patients. Subjects with higher depression score had a higher risk to had low quality of life score compared to subjects with lower depression scores ((PR 2,456, CI 1,114 – 5,412). Until now, authors had not found other studies who investigated the correlation between depression and quality of life of leprosy patients.

Other factors such as age ($x^2 = 0.237$; $p > 0.05$), educational level ($x^2 = 0.274$; $p > 0.05$), marital status ($x^2 = 0.024$; $p > 0.05$), deformity ($x^2 = 0.008$; $p > 0.05$), stigma score ($x^2 = 0.686$; $p > 0.05$), and family support score ($x^2 = 2.289$; $p > 0.05$) did not have a significant correlation with quality of life.

Educational level did not have a significant correlation with quality of life. This is comparable with the result of the study by Setyawati.[30] It might be that subjects who had basic and middle educational level had a similar quality of life score.

From this study, it was found that the presence of visible deformity caused by leprosy did not correlated with quality of life. This is contradicted with the result of the study by Tsutsumi *et al.*[18]. This difference of the results may be caused by the difference in sample size who had deformity and the difference in the operational definition of deformity in both studies.

There was no significant correlation between family support score and quality of life. This is contradicted with the result of Setyawati study who suggested that family support score was correlated with quality of life.[30] These two studies used the same instruments to measure family support and quality of life, and the sample sizes were almost similar. The difference of the results probably caused by the difference in the meaning of family support for leprosy in areas around Puskesmas Blora and leprosy patients who visited Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital.[30] In this study, there were other factors affecting the quality of life of leprosy patients, aside from family support.

Data showed that 57.1% subjects with high stigma score had low quality of life score. Nevertheless, there was no significant correlation between stigma and quality of life of leprosy patients. This is contradicted with the result of the study by Tsutsumi *et al.* who suggested that subjective stigma was correlated with the decrease in quality of life level in leprosy patients.[18] The difference in the result of the author and Tsutsumi *et al.* may be caused by the difference in the instruments to measure stigma.[18] It was also caused by the fact that for the subjects in this study, there were other factors that had more effect on quality of life, compared to subjective stigma.

The complete result of bivariate analysis is shown in the following table.

TABLE 2. The result of bivariate analysis

Variable	X^2	p	PR	CI (95%)
Gender	4.833	0.028*	9.273	0.979 – 87.868
Age	0.237	0.627	0.686	0.149 – 3.148
Marital status	0.024	0.877	0.900	0.238 – 3.406
Educational level	0.274	0.600	1.429	0.375 – 5.437
Income per month	4.804	0.028*	4.767	1.137 – 19. 977*
Deformity	0.008	0.927	0.929	0.192 – 4.500
Stigma score	0.686	0.407	1.778	0.453 – 6.972
Family support score	2.289	0.130	2.857	0.722 – 11.311
Depression score	6.415	0.011*	6.240	1.439 – 27.059*

Multivariate analysis

Multivariate analysisshowed that only depression score had significant effect on quality of life, with regression coefficient value (B) of 1.876 ($p < 0.05$; CI 1.166-36.566). The constraints in physical activity and health experienced by the subjects apparently had a big effect on mental condition, causing depression symptoms. Mental health was also one of the components of quality of life, therefore, it's natural if the quantitative analysis result showed that depression had an effect on quality of life.

The other three factors, that is age, income, and family support score, had no significant effect on quality of life, although the regression coefficient values of the three factors were high. Gender had B value of 2.616 ($p > 0.05$); income had B value of 1.448 ($p > 0,05$); and family support score had B value of 0.471 ($p > 0.05$).

Gender had no significant effect on quality of life, and this is comparable with the result of the study by Tsutsumi *et al*. But the result that income had no significant effect on quality of life was contradicted with the result of the study by Tsutsumi *et al.*[18] The difference in the results probably caused by the difference in operational definition. In Tsutsumi *et al*., the income studied was income per year, while in this study, the income studied was income per month. The result of multivariate analysis is shown in TABLE 3.

TABLE 3. The result of multivariate analysis

Variable	B	p	CI 95%
Gender	2.616	0.050	0.999 – 187.214
Income	1.448	0.095	0.777 – 23.319
Depression score	1.876	0.033*	1.166 – 36.566*
Constant	-8.016	0.004	1.166 – 36.566

CONCLUSION

There was no significant correlation between stigma and quality of life of leprosy patients.

There was a significant correlation between depression and quality of life of leprosy patients.

Depression had a considerable effect on the decrease of quality of life of leprosy patients in Dermatovenereology outpatient clinic at RSUP Dr Sardjito Hospital, compared with deformity and demographic factors.

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