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Social stigma, adherence to medication and motivation for healing: A cross-sectional study of leprosy patients at Jember Public Health Center, Indonesia

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الملخص

أهداف البحث: لا تزال الوصمة الاجتماعية المحيطة بمرضى الجذام في المجتمع مرتبطة بالتزامهم بالدواء والدافع الداخلي للشفاء. ولسوء الحظ، لم يتم تأسيس برنامج الجذام على النحو الأمثل في مراكز الصحة العامة. والهدف من هذه الدراسة هو تقييم الوصمة الاجتماعية نحو الالتزام بالدواء والتحفيز للشفاء بين مرضى الجذام في مراكز الصحة العامة في إندونيسيا.

طرق البحث: أجريت دراسة مستعرضة خلال مارس إلى مايو ٢٠١٧ في مراكز الصحة العامة في جمبر بإندونيسيا. وعملت استبانة ذاتية لجمع البيانات وتم قياس البيانات الثانوية المتعلقة بالعلاج الطبي من السجلات الطبية في مراكز الصحة العامة. وتم تحليل البيانات، واستخدام اختبار الانحدار الخطي لقياس العوامل التي يمكن أن تؤثر على الالتزام بالدواء والتحفيز للشفاء في مرضى الجذام.

النتائج: من بين ٣٥ من مرضى الجذام، كانت النسب المئوية لمرضى الجذام من نوع "قليل العصيات" ونوع "متعدد العصيات" بنسب ٢٥.٧٪ و ٧٤.٣٪ على التوالي. وكان نوع الجذام مرتبطا بطول فترة إصابة المريض بالجذام، والالتزام بالأدوية والدافع للشفاء. وكانت العوامل التي أثرت على الالتزام بالدواء والتحفيز للشفاء في مرضى الجذام هي الفترة الزمنية التي بقي فيها المريض مصابا ونوع الجذام، على التوالي.

الاستنتاجات: ارتبطت فترة العدوى ونوع الجذام بكل من الالتزام بالعلاج والدافع للشفاء في المجتمع. وينبغي توجيه المحاولات لإيجاد حالات نشطة من الجذام في

مراكز الصحة العامة. وينبغي أن تشمل هذه الأنشطة في مراكز الصحة العامة مرضى الجذام من خلال مجموعات الرعاية الذاتية لتحسين الالتزام بالدواء والتحفيز للشفاء في المجتمع.

الكلمات المفتاحية: وصمة اجتماعية؛ الالتزام بالدواء؛ الدافع للشفاء؛ مرضى الجذام، مجموعات الرعاية الذاتية

Abstract

Objectives: Social stigma surrounding leprosy patients (LPs) in the community is still related to the adherence of these patients to medication and to their internal motivation for healing. Unfortunately, the leprosy case programme has not been optimally established in public health centres (PHCs). The aim of this study was to assess the social stigma towards adherence to medication and motivation for healing among LPs in PHCs in Indonesia.

Methods: A cross-sectional study was conducted from March to May 2017 at PHCs in Jember, Indonesia. Data were collected using a self-administered questionnaire, and secondary data related to medical treatment was assessed from PHCs' medical records. The data were analysed using a *t*-test and a Chi-square test, while linear regression was used to evaluate factors that could influence LPs' adherence to medication and their motivation for healing.

Results: Among the 35 LPs in this study, 25.7% and 74.3%, respectively, had paucibacillary and multibacillary types of leprosy. The type of leprosy was associated with the length of time patients were infected with the disease,

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their adherence to medication and their motivation for healing. The factors that influenced adherence to medication and motivation for healing were the time period that the LP remained infected and the type of leprosy.

Conclusions: Infection period and type of leprosy were associated with adherence to medication and motivation for healing in the community. Efforts should be made to find active cases of leprosy at PHCs. Activities at PHCs should include self-care groups to improve LP adherence to medication and their motivation for healing in the community.

Keywords: Adherence to medication; Leprosy; Self-care; Motivation for healing; Social stigma

Introduction

Leprosy is an infectious disease that causes complex problems, particularly permanent disability.[1] Permanent disability among leprosy patients (LPs) is caused by late detection and inadequate the community medication.[2] The community perceives the disability as affecting LPs in their daily activities, life, and working ability.[3] Additionally, within the community, there exists a social stigma attached to that leprosy is a hereditary but curable disease,[4] which is related to the motivation for healing in LPs.[5] Disability among LPs brings stigma in the society; even when the disease has been declared cured, LPs still find it difficult to be accepted in the community.[6] As a result, social stigma influences a patient's adherence to medication and motivation for healing, resulting in an elevated prevalence of leprosy in the community.

The World Health Organization (WHO) reported that there were approximately 213,899 newly diagnosed patients in 2014 (a detection rate of 3.0/100,000 population), with 94% of LPs located in only 13 countries, one of which was Indonesia.[7] Indonesia's Ministry of Health reported 16,131 newly diagnosed cases of leprosy in 2014. On the other hand, the Department of Health found 498 cases of *paucibacillary* leprosy and 3337 cases of *multibacillary* leprosy[2]; the highest number of which were found in the Jember district. The Global Leprosy Strategy 2016–2020 released in April 2016 underscored its goal of "accelerating towards a leprosy-free world" and its commitment to an approach based on the principles of initiating action, ensuring accountability and promoting inclusion.[8] This programme is expected to reduce the incidence of leprosy in the community by increasing the case detection rate. It then seeks to compel LPs in the community to follow a multidrug therapy (MDT) treatment, reducing the level of disability by augmenting patient compliance with treatment.

The case detection rate of leprosy decreased in 2016, although cases of leprosy were still found in the community. This suggests that the leprosy case programme has not yet been optimally implemented. Early detection as well as regular and accurate treatment must be encouraged to avoid new cases of leprosy.[9] Disabilities caused by the disease can be prevented by regular MDT.[10] Indeed, the occurrence of disability depends on the patient's motivation to heal.[11] One of the factors that makes people reluctant to seek treatment is fear of one's condition becoming known in the community, which can lead to the LPs being ostracized by that community.[12] The intense stigma in the community associated with leprosy causes LPs to experience stress, ultimately affecting their behaviours during the treatment period.[13] It is imperative that LPs are convinced that adherence to medication can help reduce their level of permanent disability.[14] Therefore, the aim of this study was to assess the social stigma, adherence to medication and motivation for healing among LPs in a Jember public health centre (PHC) in East Java, Indonesia.

Materials and Methods

A cross-sectional study was used to examine LPs in the community from March to May 2017. The study was conducted in Jember district, which, in 2012, reported the fourth largest populations of leprosy cases in East Java, with 373 cases and defects related to a grade 2 level disability rate[2]. The sample size was selected according to the following formula $n = z^2_{1.96-\propto} \cdot \frac{p.q}{d}$, with 95% confidence intervals, and in light of a previous study's case detection rate for LPs in the community of 10%.[2] Consequently, 35 participants were involved in this study. Participants were selected using random sampling. Those included in this study were selected according to the following inclusion criterion: LPs were registered at the PHCs, they were undergoing treatment, and they were willing to participate in the study. Meanwhile, LPs with young children and those who were unable to communicate were excluded.

The instrument used for this study was a self-administered questionnaire. A socio-demographic questionnaire recorded age, gender, education background, marital status, and living condition. Secondary data was obtained from PHC (medical record) and identified the type of leprosy, the degree of disability, infection period, treatment, medication history, and attendance in self-care groups. To measure social stigma, we used the Internalized Stigma of Mental Illness (ISMI) scale, consisting of 28 items assessed with Likert scales (strongly disagree = 1 to strongly agree = 4). A Bahasa Indonesian version of the scale from an earlier study was used (Cronbach alpha 0.96).[15] Higher scores indicate higher social stigma within the community. Meanwhile, a patient's adherence to medication was measured using the *Morisky Medication Adherence Scale* (MMAS). This scale consists of 8 items assessed with dichotomous choices (yes = 1, no = 0). An Indonesian version from a previous study was used (Cronbach alpha 0.80).[16] Here, higher scores indicate a lower adherence to medication among LPs. Finally, to measure a patient's motivation for healing, our assessment

tool consisted of 6 items in a Likert scale (strongly agree = 4 to not agree = 1). Here, too, we relied on a previous study that used a Bahasa Indonesian version of the scale (Cronbach alpha = 0.83).[17] In this scale, a higher score indicates higher LP motivation to heal.

Ethical consideration

After explaining the study's objectives, we obtained informed consent from each participant. Ethical permission to carry out this study was granted by the Research Ethical Committee at the School of Nursing, University of Jember. The confidentiality of the data was ensured for all participants.

Data management

Data were coded and analysed using the Statistical Package for the Social Sciences (SPSS) version 22.0 (IBM, 2015). Quantitative data are presented as means ± standard deviations (SD) while qualitative data are presented in terms of frequencies and proportions. Student's t-tests were used to compare quantitative data between paucibacillary and multibacillary groups, while a Chi-square test was used for between-group comparisons of qualitative data. Finally, a linear regression was used to assess the relationship among different socio-demographic variables, social stigma, adherence to medication and motivation for healing among LPs in the community. In this study, the threshold of statistical significance was set at p value less than 0.05.

Results

The socio-demographic data of participants are shown in Table 1. Among the 35 participants, the mean age was 44.9 ± 16.6 years, and 74.3% were males and 25.7% were females. The infection period mean was 7.8 ± 4.5 month, with 25.7% of the respondents suffering from paucibacillary leprosy and 74.3% with multibacillary leprosy. A total of 11.4% of LPs had stopped taking their medications, with the degree of disability at the 0 and 2 levels being 94.3% and 5.7%, respectively. The mean scores for social stigma, adherence to medication and LP motivation for healing in the community were 70.2 ± 11.4, 3.1 ± 2.2 and 19.2 ± 3.6, respectively.

Table 2 shows that there were significant differences between infection time, adherence to medication, motivation for healing and type of leprosy ($p < 0.05$). LPs with multibacillary leprosy were diagnosed considerably earlier than those with paucibacillary leprosy (8.6 months vs. 5.7 months). Meanwhile, LPs with paucibacillary leprosy had lower adherence to medication than those with multibacillary leprosy. On the other hand, LPs with multibacillary leprosy had higher motivation for healing than those with paucibacillary leprosy.

A regression model was used to examine predictors of adherence to medication (Table 3) and motivation for healing (Table 4) among LPs in the community. The regression model for adherence to medication was significant, $F = 1.68$; $p < 0.05$, and its variables accounted 41.3% of variance in adherence to medication scores. The

Table 1: Participants' sociodemographic variables, leprosy history, social stigma, adherence to medication and motivation for healing (n = 35).

Variable	n (%)
Age (year)	
Mean (SD)	44.9 (16.6)
Gender	
Male	26 (74.3)
Female	9 (25.7)
Education level	
Not attending school	5 (14.3)
Elementary school	21 (60.0)
Junior high school	4 (11.4)
Senior high school	4 (11.4)
College	1 (2.9)
Marital status	
Single/not yet married	6 (17.1)
Married	24 (68.6)
Divorced/Widowed	5 (14.3)
Living condition	
Alone	1 (2.9)
Family	34 (97.1)
Infection time (month)	
Mean (SD)	7.8 (4.5)
Attendance self-care groups	
Yes	33 (94.3)
No	2 (5.7)
Type of leprosy	
Paucibacillary (PB)	9 (25.7)
Multibacillary (MB)	26 (74.3)
Medication treatment	
Drop out	4 (11.4)
No drop out	31 (88.6)
Degree of disability	
0	33 (94.3)
1	0
2	2 (5.7)
Social stigma	
Mean (SD)	70.17 (11.44)
Adherence to medication	
Mean (SD)	3.14 (2.17)
Motivation for healing	
Mean (SD)	19.2 (3.64)

diagnosed period factor had significant main effects ($B = 0.61$, *Std Error* = 0.09, $t = 3.14$, $p = 0.004$). Meanwhile, the regression model for motivation for healing was significant, $F = 2.29$; $p < 0.05$, and its variables accounted for 48.9% of the variance in motivation for healing scores. Type of leprosy as a factor also demonstrated significant main effects ($B = 0.42$, *Std Error* = 1.46, $t = 2.34$, $p = 0.028$). Finally, in this study, social stigma was found not to be associated with adherence to medication ($B = 0.01$, *Std Error* = 0.03, $t = 3.14$, $p = 0.948$) nor with motivation for healing ($B = -0.03$, *Std Error* = 0.05, $t = 3.14$, $p = 0.881$) among LPs in the community.

Discussion

The current study examined the degree to which social stigma, adherence to medication and motivation for healing among LPs in PHCs were associated with type of leprosy. On

Table 2: Differences in sociodemographic, social stigma, adherence to medication and motivation for healing by type of leprosy (n = 35).

Variable	Paucibacillary n (%)	Multibacillary n (%)	t/X^2	p
Age (year)				
Mean (SD)	40.8 (21.0)	46.3 (15.1)		
Gender				
Male	6 (66.7)	20 (76.9)	0.027	0.869
Female	3 (33.3)	6 (23.1)		
Education level				
Not attending school	0	5 (19.2)	3.403	0.493
Elementary school	6 (66.7)	15 (57.7)		
Junior high school	2 (22.2)	2 (7.7)		
Senior high school	1 (11.1)	3 (11.5)		
College	0	1 (3.8)		
Marital status				
Single/not yet married	2 (22.2)	4 (15.4)	0.274	0.872
Married	6 (66.7)	18 (69.2)		
Divorced/Widowed	1 (11.1)	4 (15.4)		
Living condition				
Alone	1 (11.1)	0	0.318	0.573
Family	8 (88.9)	26 (100)		
Infection time (month)				
Mean (SD)	5.7 (2.8)	8.6 (4.8)	−2.217	0.036*
Attendance self-care groups				
Yes	9 (100)	24 (92.3)	0.001	0.981
No	0	2 (7.7)		
Medication history				
Drop out	1 (11.1)	3 (11.5)	0.000	1.000
No drop out	8 (88.9)	23 (88.5)		
Degree of disability				
0	9 (100)	24 (92.3)	0.734	0.392
1	0	0		
2	0	2 (7.7)		
Social stigma				
Mean (SD)	66.3 (8.2)	71.5 (12.2)	−1.417	0.171
Adherence to medication				
Mean (SD)	4.4 (2.3)	2.7 (2.0)	2.201	0.035*
Motivation for healing				
Mean (SD)	16.7 (5.4)	20.1 (2.4)	−2.620	0.013*

Note. t = determined using independent t-test. X^2 = determined using Chi-square test. *p < 0.05.

the other hand, diagnosis period and type of leprosy were found to be factors associated with adherence to medication and motivation for healing in LPs in the community. These findings were similar to those found in a previous study which had confirmed that type of leprosy was related to degree of disability[18] and case detection of leprosy was determined by medication of LPs.[19]

In this study, the prevalence of paucibacillary LPs was greater than that of multibacillary LPs. This finding reflects the fact that PHCs applied early case detection to find the LPs in the community. Case finding within the community is the critical element in the active surveillance of a public health setting.[6] Paucibacillary LPs were found to have lower adherence to medication than multibacillary LPs, a finding that was congruent with previous research on the adherence and maintenance of treatment[20]. This finding may be because signs and symptoms of paucibacillary leprosy are less complex compared to those of multibacillary leprosy. On the other hand, patients with multibacillary leprosy had longer diagnosis times, although they were identified to have higher motivation for healing than patients with paucibacillary leprosy, similar to a previous study on motivation among LPs to follow their medication regime.[21] Therefore, active, self-detection among LPs could improve insight and encourage them to join self-care groups at the PHCs.

In the present study, the diagnosis period of leprosy was a factor influencing adherence to medication, a finding consistent with earlier research on the monitoring and controlling of leprosy medication systems.[9] Perhaps this reflects the fact that both infection period and case detection are related to medication,[22] and to the of LPs following the medication MDR − itself associated with first diagnosis of the disease.[1] This finding suggests that early diagnosis and early treatment should be conducted at PHCs in order to increase adherence to medication among LPs in the community.

Our findings showed that type of leprosy was associated with motivation for healing in LPs. This is consistent with a previous study that reported that LPs' motivation to heal was determined by leprosy type and the availability of programmes in the community.[23] In the case of LPs, paucibacillary and multibacillary status was related to MDR therapy.[5] Therefore, LPs should be supported by their family at the family healthcare system.[24] This finding suggests that health promotion should be designed so that LPs can increase their motivation for healing that is based on family settings and the community.

Table 3: Linear regression of factors influencing adherence to medication of leprosy patients (n = 35).

Variable	Unstandardized Beta	Standard Error	Standardized Beta	t	p
Age	−0.003	0.025	−0.024	−0.128	0.899
Gender	0.042	0.867	0.009	0.049	0.962
Education level	2.149	1.328	0.351	1.618	0.119
Marital status	−0.531	0.827	−0.115	−0.643	0.527
Living condition	2.874	2.548	0.224	1.128	0.270
Type of leprosy	−1.818	0.935	−0.371	−1.945	0.064
Infection time	0.302	0.096	0.628	3.139	0.004**
Medication history	−0.975	1.335	−0.145	−0.731	0.472
Degree of disability	−0.469	0.799	−0.102	−0.587	0.563
Social stigma	0.002	0.034	0.012	0.066	0.948

Note. **p < 0.01.

Table 4: Linear regression of factors influencing motivation for healing of leprosy patients (n = 35).

Variable	Unstandardized Beta	Standard Error	Standardized Beta	t	p
Age	−0.043	0.039	−0.198	−1.119	0.274
Gender	−2.255	1.358	−0.274	−1.661	0.110
Education level	0.327	2.079	0.032	0.157	0.876
Marital status	0.882	1.294	0.114	0.682	0.502
Living condition	−8.166	3.989	−0.379	−2.047	0.052
Type of leprosy	3.421	1.463	0.416	2.338	0.028*
Infection time	−0.170	0.151	−0.210	−1.126	0.271
Medication history	0.199	2.089	0.018	0.095	0.925
Degree of disability	0.878	1.250	0.113	0.702	0.489
Social stigma	−0.008	0.054	−0.026	−0.151	0.881

Note. *$p < 0.05$.

Furthermore, in this study, social stigma was not associated with adherence to medication and motivation for healing in LPs in the community. This phenomenon contradicts a previous study of LPs in Nepal that found a relationship between social stigma and treatment.[14] This discrepancy may be due to the sociocultural particularities of the Indonesian context. On the other hand, when measuring social stigma with psychometric tools, it was found to correlate with the social and cultural background of patients, as confirmed in previous studies.[25,26] Evidence-based studies show that social stigma is influenced by how the community perceives the social problem, and that it marginalizes the at-risk population in the community.[1,27] Consequently, tools for the assessment of social stigma within an Indonesian context should be developed and validated.

The present study has certain limitations, including those related to the measurement of adherence to medication and to the motivation for healing. Indeed these measures could differ from on study to another based on how they define their variables and the sample size. The sample of LPs recruited for this study may not be representative of the Indonesian population in general. However, a community condition was included in the study, one composed of a range of individuals occupying different socio-economic positions and composed of a dynamic population structure. The use of purposive sampling, along with the social desirability bias, limited the generalization of these results. In addition, the research was designed as a cross-sectional study, which also limited the generalization of the study.

Conclusions

In conclusion, this study demonstrated that diagnosis period and type of leprosy were factors associated with adherence to medication and motivation for healing among LPs in the community. These results suggest that case findings should be assessed to facilitate the early detection of LPs. Furthermore, in future studies, PHCs could involve LPs in self-care groups to help evaluate adherence to medication and their motivation for healing in the community.

Conflict of interest

The authors have no conflict of interest to declare.

Ethical approval

This study was approved by the Department of Health of Jember, with No. 440/16915/311/2017.

Authors' contribution

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