Disability Grades and Quality of Social Relationships among People with Leprosy in Donorojo Leprosy Rehabilitation Village

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Abstract

Objective: Disabilities among people with leprosy may affect their quality of life and alter their satisfaction toward various aspects of life, including social relationships. Social relationships encompass all aspects of personal relationships, social support, and sexual activities. Thus, it important to explore the association between the degree of disability and social relationships.

Methods: This cross-sectional study involved 89 patients with leprosy who lived in the Donorojo Leprosy Rehabilitation Village.

Results: Our analysis showed that 77.5% of the respondents had grade 2 disabilities and that the average social relationship score was 69.72 of 100. Correlation between disability grades and social relationship domains was found \( p = 0.032 \). Limitations in interaction and social participation increased with increasing disability grades.

Conclusion: Provision of facilities and assistance from the Donorojo Leprosy Rehabilitation Unit is expected to improve the quality of life of the patients with leprosy.

Keywords: disability grade; leprosy; people affected by leprosy; quality of life; social relationships

Introduction

Hansen’s disease, commonly called leprosy, is the oldest chronic communicable disease and is one of the prevailing public health problems in Indonesia¹. The discovery of level 2 disability is the main indicator that a program is successful. Based on the data of the Ministry of Health, the overall number of patients with level 2 disability among a population of 1,000,000 has increased from 6.3 in 2014 to 6.6 in 2015. Physical disabilities might occur owing to Mycobacterium leprae, the causative agent of leprosy, which infects the peripheral nerves, upper respiratory tract mucous membrane, skin, and conjunctiva. If not effectively treated, this may cause progressive damages that lead to physical defects¹. The World Health Organization (WHO) classifies disability grades into three levels: level 0, no sensory and conjunctiva problems; level 1, any sensory disturbances in the upper and/or lower extremities; and level 2, defects in both extremities and heavy conjunctiva disruption².

The level of disabilities may affect the quality of life of patients with leprosy, such as experiencing discriminations as the disability grade worsens. A study in Western Nepal showed that 20.7%, 28.1%, and 51.2% of the respondents with level 0, 1, and 2, respectively, experienced discrimination³. A visible physical disablement becomes the highest risk factor of perceived and enacted stigma occurrence among patients with leprosy and those who previously had leprosy.

Barriers in performing daily activities, rising discrimination and stigma, and physical disablement may influence the quality of life and social relationships. WHO⁴ describes quality of life as an individual perception of one’s life in terms of culture, hopes, and standard aspects related to physical health, psychological health, social relationships, and the environment. Social relationship domains encompass personal relationships, social supports, and sexual activities. In the Netherlands, social impacts on 31 respondents showed that 39% of them felt “different” or “somehow weird” because they had been infected with leprosy, 71% had limited social activities, and 48% reported limited physical interactions at work and social activities, of which 35% reported difficulties in meeting someone; yet, they were afraid to be rejected and questioned about their conditions⁵.

Another study evaluated disabilities affecting sexual activities. In South Africa, 16 of 30 respondents were
neglected by their partners owing to them being unable to provide “safety” (in psychological, social, and economical terms) related to sexual activity\(^6\). Ten respondents also experienced family rejection, and 20 reported being rejected by friends.

Data on the quality of life, particularly with respect to social relationships, is essential for nurses as they are health workers who assess every aspect of human living, that is, biologically, psychologically, socially, spiritually, and culturally\(^7\). With the importance of data availability in social relationship quality, which is influenced by physical disabilities, only few studies have focused on patients with leprosy. Therefore, this study aimed to identify the correlation between the disability grades and quality of social relationships among people with leprosy in Donorojo, Central Java.

**Methods**

This cross-sectional study included total 99 respondents. The respondents were patients with leprosy and were still living in the Donorojo Rehabilitation Village, Central Java. The tools employed were the disability grade questionnaire (Kriteria Klasifikasi Tingkat Kecacatan Kusta) by the Indonesian Ministry of Health and WHOQOL-BREF social relation quality questionnaire, which was translated into Bahasa Indonesia by Mardiati et al.\(^8\). Univariate analysis was described by proportion and central tendencies, whereas bivariate analysis was performed using one-way analysis of variance.

**Results**

Ten respondents were excluded; thus, the total number of respondents was reduced to 89. The distribution of disability grades, social relation qualities, and relationship between disability and social relationship is shown in Tables 1–3.

**Table 1. Distribution of Respondents Based on Disability Grades in Donorojo Rehabilitation Village, Central Java, April 2017 (n = 89)**

<table>
<thead>
<tr>
<th>Grade of disablement</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 0 disablement</td>
<td>9</td>
<td>10.1</td>
</tr>
<tr>
<td>Grade 1 disablement</td>
<td>11</td>
<td>12.4</td>
</tr>
<tr>
<td>Grade 2 disablement</td>
<td>69</td>
<td>77.5</td>
</tr>
</tbody>
</table>

Our results showed that the incidence of grade 2 disabilities was the highest among respondents (77.5%), which indicates that most of them might have had a delay in leprosy management and therapy, which induced disabilities.

**Table 2. Distribution of Respondents Based on Social Relationship Quality in Donorojo Rehabilitation Village, Central Java, April 2017 (n = 89)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>95% CI</th>
</tr>
</thead>
</table>

As observed in Table 2, 39 respondents had a social relationship quality below the mean (69.72), whereas 49 had a quality above the mean.

**Table 3. Relationships between Disability Grades and Social Relationships Quality in Donorojo Rehabilitation Village, Central Java, April 2017 (n = 89)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Disability Grades</th>
<th>n</th>
<th>Mean</th>
<th>Range</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social</td>
<td>Grade 0 disablement</td>
<td>9</td>
<td>33.78</td>
<td></td>
<td>0.032</td>
</tr>
<tr>
<td>Relationships</td>
<td>Grade 1 disablement</td>
<td>11</td>
<td>61.64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality</td>
<td>Grade 2 disablement</td>
<td>69</td>
<td>43.81</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As revealed by bivariate analysis, one-way analysis of variance showed a significant relation between disability grades and the social relationship quality domain (α =0.05).

**Discussion**

Statistical analysis revealed a significant relationship between disability grades and the social relationship quality domain. This finding is consistent with the study of Reis et al. 2013\(^9\), which showed that respondents with grade 0 disablement had a higher social relationship quality domain than those with grade 1 and 2 disablements. Moreover, there was a significant relationship between disablement grades and the social relationship domain (p=0.03).

Additional information was also obtained when interviewing the respondents. Those affected with leprosy reported difficulties in social interactions because of physical limitations, such as wounds and defects, which rendered them unable to walk. This situation limited their interactions with others and rendered them unable to join social organizations, because they would only sit or rest at home.

People with leprosy and acquired disabilities face difficulties in daily activities, feel uncomfortable to participate in social activities and visit public places, cannot accept that they have acquired the disease, and refer to themselves as failures after being diagnosed with leprosy\(^10\). Physical disabilities acquired after being infected with leprosy are also one of the main reasons of discrimination. The disability grades could change the quality of life of those affected with leprosy. In fact, discrimination occurs as the disablement grade increases. A study conducted in Western Nepal showed that 20.7%, 28.1%, and 51.2% of respondents with grade 0, 1, and 2 disabilities, respectively, felt discriminated\(^11\). A visible physical disablement becomes the highest risk factor of perceived and enacted stigma occurrence in patients with leprosy and those who previously had leprosy.

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33
Another study showed that the results of the inter-grade social relationship domain were not quite different. In addition, statistical analysis did not show any significant relationships between the disablement grades and social relationship domain (p=0.17; α=0.05) (Brouwers et al., 2012). Although the respondents in Brouwers et al.’s study reported difficulties in maintaining social relationships, such as not being allowed to be involved in community activities, those behaviors were not statistically related to respondents’ disablement grades.

**Conclusion**

Our study results revealed a significant statistical relationship between the grades of disablement and social relationship domain. A higher disablement grade causes various obstacles in physical mobility, which leads them to staying at home and making less social interactions and social involvement. Stigmas and discriminations arise because of physical defects, which instill fear among those with leprosy and unwillingness to interact with their community.

This study may serve as reference among nurses in formulating leprosy-related health education, so that novice health workers, particularly nurses, can understand the social effects of leprosy. Our results can serve as a reference for seminars and trainings related to appropriate self-management and prevention of wound progression. The Donorojo Leprosy Rehabilitation Unit of Kelet Region Hospital (Unit Rehabilitasi Kusta Donorojo RSUD Kelet) may use the present study findings for a patient’s benefit.

In the future, we hope to conduct other advanced investigations about the social relationship domains among those affected with leprosy, particularly by comparing social relationship domains between those who live in the rehabilitation village and those who live in communities.

**Acknowledgment**

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**References**