Social acceptance and quality of life of leprosy patient

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Abstract. Some of the leprosy patients facing problems in many aspects such as social, economic, cultural and national security. Both the debilitating effects and disfigurements of leprosy, the society tends to stigmatize negatively those suffering from leprosy. The impact of negative stigma on society causes depression and problems in workplace cause difficulty in patient’s daily life. Neuropathic pain disturbs the quality of life of leprosy patients which could become so severe and significant. The neuropathic pain will lower their productivity which later caused difficulties in finding a job. This study was an analytical observational study to identify the correlation between neuropathic pain and quality of life in Leprosy Hospital of Scanning in Medan Belawan. The result showed that there is a correlation between neuropathic pain and disruption of quality of life (p=0.017). In conclusion, the milder the neuropathic pain experienced by persons with leprosy, the less the quality of life will be disturbed.

1. Introduction
According to WHO, 211,973 new cases encountered leprosy from 106 countries in 2015. Countries with a higher incidence of leprosy India, Brazil, and Indonesia[1]. Leprosy is a chronic infectious disease caused by Mycobacterium leprae, acid-fast bacilli bacteria. Many people who have experienced leprosy were compounded by many factors such as social, economic, cultural and national security[2]. In 2014 and 2015, WHO launched the Global Leprosy Strategy 2016-2020: Accelerating towards a leprosy-free world, which aims to reinvigorate efforts to control leprosy and avert disabilities[3]. The neuropathic pain will lowered their productivity and damage their quality of life and causes difficulties in getting a job. Most studies conducted to a relationship between neuropathic pain and the quality of life aspects in leprosy patients[4][5][6]. With lack of knowledge about leprosy and its disability in the society, causes patients to experience negative stigma which also makes them hesitated going to the treatment that eventually can lead to vicious circle[1]. The aim of this study to review the stigma from society, simultaneously analyse the relation between neuropathic pain and quality of life in leprosy patient.

2. Research Methods
A descriptive study among 100 leprosy patients was recruited consecutively from Leprosy Hospital of Sicanang in Medan. This study is done in March-April 2017. The samples inclusion criteria are all leprosy patients who registered at Sicanang hospital. Data on neuropathic pains, social acceptance,and quality of life were obtained using validated questionnaires. Spearman correlation was performed to see the correlation between neuropathic pain and social acceptance, with the quality of life.
3. Results

3.1. Individual Characteristics
The process of data collection was done directly at the hospital compound where all sample resided. Characteristic of leprosy patients are listed in the following table.

Table 1. Demographic characteristics of study participants.

| Characteristics          | Categories      | n  |
|--------------------------|-----------------|----|
| Gender                   | Males           | 48 (48) |
|                          | Females         | 52 (52) |
| Age Group (years)        | 11-20           | 1 (1)  |
|                          | 31-40           | 11 (11) |
|                          | 41-50           | 33 (33) |
|                          | 51-60           | 40 (40) |
|                          | 61-70           | 8 (8)   |
|                          | 71-80           | 4 (4)   |
|                          | > 80            | 3 (3)   |
| Education                | Not attending   | 40 (40) |
|                          | Elementary School | 45 (45) |
|                          | Junior High School | 9 (9)  |
|                          | Senior High School | 6 (6)  |
| Jobs                     | Employment      | 22 (22) |
|                          | Unemployment    | 78 (78) |
| Type of Pain             | Nociceptive     | 14 (14) |
|                          | Neuropathic     | 86 (86) |
| Depression Grade         | Not depressed   | 31 (31) |
|                          | Mild depression | 63 (63) |
|                          | Moderate depression | 4 (4) |
|                          | Severe depression | 2 (2) |
| Physical Limitation      | Limited         | 97 (97) |
|                          | Unlimited       | 3 (3)   |

3.2. Analysis of Social Acceptance
Data on discrimination against leprosy patients are depicted in Table 2 below. The discrimination is highest at school and finding jobs with 21% and 19%, respectively. This followed with at public transportation and worship places which both contributed 11%. Ten percent of discrimination when seeking health care. Both marriage and going to store contributed a discrimination of 6%.

Table 2. Discrimination characteristics of study participants.

| Discrimination           | Frequency (F) | Percentage (%) |
|--------------------------|---------------|----------------|
| Forced to leave School   |               |                |
| Yes                      | 21            | 21             |
| No                       | 79            | 79             |
| Marriage                 |               |                |
| Yes                      | 6             | 6              |
| No                       | 94            | 94             |
| Refused for Employment   |               |                |
| Yes                      | 19            | 19             |
| No                       | 81            | 81             |
| Public Transportations   |               |                |
| Yes                      | 11            | 11             |
| No                       | 89            | 89             |
| Refused in prayer places |               |                |
3.3. Association of neuropathic pain and quality of life

Table 3. Comparison between neuropathic and quality of life of study participants.

| Quality of Life | Poor n (%) | Good n (%) | Total n (%) | r     | p    |
|----------------|------------|------------|-------------|-------|------|
| Neuropathic Pain |            |            |             |       |      |
| Yes             | 41 (41.0%) | 45 (45.0%) | 86 (86.0%)  |       |      |
| No              | 2 (2.0%)   | 12 (12.0%) | 14 (14.0%)  | -0.239| 0.017|
| Total           | 43 (43.0%) | 57 (57.0%) | 100 (100.0%)|       |      |

The majority of leprosy patients (41.0%) experience neuropathic pain and disruption in quality of life. Using Spearman correlation, this research found a coefficient correlation of -0.239. This is interpreted as a significant weak correlation (p<0.05) between neuropathic pain and quality of life.

3.4. Regression analysis of neuropathy paint to quality of life

Table 4. Regression analysis.

| Model          | R       | Determination Coefficient | Regression Coefficient | Significance |
|----------------|---------|---------------------------|------------------------|--------------|
| Constants      | 0.269   | 0.072                     | 65.976                 | 0.000        |
| Neuropathic Pain | -1.843 | 0.007                     |                        |              |

Table 4 shows the coefficient (R squared) of 0.072 (7.2%) is obtained by regression analysis. This is showing that neuropathic pain contributes as much as 7.2% to the patient’s quality of life. The other 92.8% is contributed by other factors. The given formula of the regression is calculated as y = 65.976 + (-1.843) x.

4. Discussion
This study showed that most dominant pain is a neuropathic pain (86%), while 14% patients have nociceptive pain. Fifty-seven percent of leprosy patients do not have a disruption in quality of life, while 43% of them have a disruption in quality of life. Haroun OM found different results using Douleurneuropathque en 4 (DN4) and The Leads Assessment of Neuropathic Symptom and Sign (LANSS) questionnaires. Sixty percent out of 80 samples experienced pain, in which 43% with nociceptive pain and 11% with neuropathic pain and 6% with mixed pain[7].
4.1. Correlation of neuropathic pains with quality of life
The result shows a significant weak correlation between neuropathic pain with the quality of life ($r=0.239$). This is interpreted that the milder neuropathic pain experienced by a patient, the better his/her quality of life. Costa MD (2012) mentions that there was a significant correlation between pain and quality of life with details of physical and psychological ($p<0.001$) and social aspects ($p=0.039$), and environmental aspects ($p=0.029$). Some studies highlight the association of chronic pain with anxiety, depression, poor quality of sleep and a reduced capacity to perform daily and occupational activities, and suggest that it also impairs participation in social factors should be investigated in the future. Finally, it is important to continue research in this field to identify whether a reduction in perceived levels of pain leads over time to a decrease in psychological distress, and a better quality of life.

4.2. Correlation of neuropathic pains with physical limitation and depression grade
Based on research which uses DN4 questionnaire by Larry-Levy E (2011) shows that 41% of patients with neuropathic pain have psychological morbidities ($p=0.0001$), such as sleep disorder, anxiety, and mild depression. In this study, we found that the most dominant degree of depression was mild (63%), followed by no depressed (31%), moderate and severe depression with 4% and 2%, respectively. A study found that seventy percent of leprosy patients suffered from moderate or severe depression. The deformity impacts significantly found on the mental health of leprosy patients. Patients’ actual experiences of being discriminated against, for example, being physically attacked by people and refused shopping amenities, were associated with higher CES-D scores (The Center for Epidemiologic Studies Depression Scale).

Leprosy may affect body image and self-esteem. The stigma that goes with this disease may result in restrictions of social participation. Because of that, individuals need professional, family and social support. A relevant question to be evaluated is the perspective of the patient regarding the disease, the treatment, the perception of the need for care and limitations imposed from a personal, social and working point of view. After discharge, many patients still need assistance due to the complications in the health sector, resulting in pain and insecurity.

5. Conclusions
A central issue of this study was the quality of life and the social acceptance of persons that were affected by leprosy. The study found an association between pain and quality of life in which the milder the neuropathic pain experienced by persons with leprosy, the less the quality of life will be disturbed. Fifty-seven percent of samples in this study did not experience disruption in quality of life. Nonetheless, the persons who suffered from leprosy will face discrimination in many factors and commonly experienced mild depression.

In many ways, to change today’s society stigmatize and discrimination, it’s recommended for guidance and empowerment as well as knowledge of leprosy from the government to the people. It is also important that researchers concerned an effective communication method in future studies.

References
[1] WHO 2016 Leprosy: Fact sheet Available from: www.who.int/mediacentre/factsheet/fs [Accessed: October 31, 2016]
[2] Kementerian Kesehatan Republik Indonesia Direktorat Jenderal Pengendalian Penyakit dan Penyehatan Lingkungan 2012 Pedoman nasional program pengendalian penyakit kusta (Jakarta: Bakti Husada)
[3] Larry-Levy 2011 Neuropathic pain and psychological morbidity in patients with treated leprosy: a cross-sectional prevalence study in Mumbai PLoS Negl. Trop. Dis. 5(3) e981
[4] Costa M D 2012 Assessment of quality of life of patients with leprosy reactional states treated in a dermatology reference center An. Bras. Dermatol. 87(1) 26-35
[5] Santos V S 2016 Pain and quality of life in leprosy patients in endemic area of northeast Brazil: a cross-sectional study Infect. Dis. Poverty 5 18
[6] Garbin C A, Garbin A J and Carloni M E 2015 The stigma and prejudice of leprosy: influence on the human condition Rev. Soc. Bras. Med. Trop. 28(2)
[7] Haroun 2012 Investigation of neuropathic pain in treated leprosy patients in Ethiopia: A cross-sectional study Pain 153 1620-4
[8] Singh and Gurvinder P 2012 Psychosocial aspects of Hansen’s disease (Leprosy) Ind. Dermatol. Online J. 3(3) 166-70
[9] Seshadri D 2014 The tangled web: a study of knowledge and attitude towards leprosy from a tertiary care hospital India Ind. J. Lepr. 86 27-41
[10] Barbosa J C 2009 Participation level of the leprosy patients in society Ind. J. Lepr. 81 18