

Dermatology Life Quality Index of Leprosy Patients in Thailand.

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ABSTRACT:

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Background: Leprosy is a chronic, gradually progressive infectious disease caused by *Mycobacterium leprae*. The manifestations involve mainly the skin and the peripheral nerves, which can progress to various deformities affecting patients' quality of life including mental aspect, social stigma and many economic problems.

Objective: To evaluate the quality of life of patients with leprosy in Thailand and other personal contributing factors.

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Materials and Methods: The leprosy patients who attended the Hansen's clinic at Siriraj Hospital and Ratchapracha Samasai Institute between May and November 2012 were asked to complete the Dermatology Life Quality Index (DLQI) questionnaires in Thai version. The demographic data, type of the disease, area of lesions, associated symptoms, and the amount of families or friends who knew about the disease were recorded.

Results: Seventy-five patients voluntarily answered the questionnaires. Most of them were male (73.3%) and 65.3% of the cases worked as labor, with a mean (SD) age of 46.8 (15.5) years. Sixty of them (80%) were diagnosed as multibacillary (MB) leprosy. The mean (SD) of total DLQI scores were 7.29 (5.88) with a range of 0-29. From 10 questions, the highest mean scores were observed in the second question concerning the patients' embarrassment with a mean (SD) of 1.27 (1.12). There was no significant relationship between age ($p = 0.25$), gender ($p = 0.56$) or employment status ($p = 0.90$) with total DLQI scores. However, from multiple logistic regression, patients with multibacillary (MB) leprosy had a significant higher DLQI scores than paucibacillary (PB) group with adjusted odds ratio of 13.83 (95% CI OR 1.65-115.58, $p = 0.015$). Moreover, the patients with facial lesion also scored significantly higher than those without facial involvement with adjusted odds ratio of 3.54 (95% CI OR 1.18-10.68, $p = 0.025$).

Conclusions: From DLQI score of leprosy patients in this study, it indicates the moderate impact of the disease on quality of life, especially in those with multibacillary group and those with lesions on the face.

Key words: Dermatology Life Quality Index, Leprosy

บทคัดย่อ:

เพ็ญวดี พัฒนปรีชากุล, สราญจิต วิมูลชาติ, อรจุกา ชัยวนนท์, กมลพรรณ เลิศรุจิวิช, พชร เอี่ยมธาราชัย, กนกวลัย กุลทนต์ การศึกษาคุณภาพชีวิตด้านผิวหนังในผู้ป่วยโรคเรื้อน วารสารโรคผิวหนัง 2555; 28: 159-168.

ภาควิชาดจวิทยา คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล

สถาบันราชประชาสมาสัย กรมควบคุมโรค กระทรวงสาธารณสุข

ภูมิหลัง: โรคเรื้อนเป็นโรคติดเชื้อเรื้อรังที่ผิวหนังและเส้นประสาทส่วนปลายที่เกิดจากเชื้อ *Mycobacterium leprae* ซึ่งก่อให้เกิดรอยโรคและความพิการทางกายแก่ผู้ป่วย นอกจากนี้ยังมีผลกระทบต่อคุณภาพชีวิต สภาพจิตใจรวมทั้งทางด้านสังคมและเศรษฐกิจที่เกี่ยวข้องกับผู้ป่วยอีกด้วย

วัตถุประสงค์: เพื่อศึกษาคุณภาพชีวิตด้านผิวหนังในผู้ป่วยโรคเรื้อนรวมทั้งปัจจัยอื่นๆที่สัมพันธ์กัน

วิธีการศึกษา: เป็นการสัมภาษณ์ผู้ป่วยโรคเรื้อนที่มารับการรักษาที่คลินิกแสนเขน โรงพยาบาลศิริราช และคลินิกผิวหนังเนือชา สถาบันราชประชาสมาสัย กรมควบคุมโรค ระหว่างเดือนพฤษภาคมถึงเดือนพฤศจิกายน พ.ศ. 2555 จำนวน 75 ราย โดยใช้แบบสอบถามคุณภาพชีวิตด้านผิวหนังฉบับภาษาไทย

ผลการศึกษา: ผู้ป่วยสมัครใจตอบแบบสอบถามทั้งหมด 75 ราย โดย 65.3% ของผู้ป่วยทั้งหมดมีอาชีพรับจ้าง ผู้ป่วยส่วนใหญ่เป็นเพศชาย (73.3%) อายุเฉลี่ย (SD) คือ 46.8(15.5) ปี ผู้ป่วยจำนวน 60 ราย(80%) ได้รับการวินิจฉัยเป็น โรคเรื้อนชนิดเชื้อมาก โดยมีค่าเฉลี่ยของคะแนนรวม DLQI เท่ากับ 7.29(5.88) โดยมีคะแนนตั้งแต่ 0-29 และจากคำถาม ทั้งหมด 10 ข้อพบว่าข้อที่มีค่าคะแนนสูงที่สุดคือข้อที่ 2 ซึ่งเป็นข้อที่เกี่ยวข้องกับความรู้สึกลบอายและการขาดความมั่นใจซึ่ง มีคะแนนเฉลี่ย (SD) เท่ากับ 1.27(1.12) จากการศึกษาครั้งนี้เราไม่พบความสัมพันธ์ระหว่างอายุ ($p = 0.25$) เพศ ($p = 0.56$) และ อาชีพของผู้ป่วย ($p = 0.90$) กับค่าเฉลี่ยของคะแนน DLQI นอกจากนี้ยังพบว่าผู้ป่วยในกลุ่มเชื้อมากจะมีค่าเฉลี่ยของคะแนน DLQI มากกว่าผู้ป่วยในกลุ่มเชื่อน้อยอย่างมีนัยสำคัญทางสถิติโดยมีค่า adjusted odd ratio เท่ากับ 13.83 (95%CI OR 1.65-115.58, $p = 0.015$) และพบว่าผู้ป่วยที่มีรอยโรคบริเวณใบหน้าจะมีค่าเฉลี่ยของคะแนน DLQI มากกว่าผู้ป่วยที่ไม่มีรอยโรคที่ ใบหน้าโดยมีค่า adjusted odd ratio เท่ากับ 3.54 (95%CI OR 1.18-10.68, $p = 0.025$)

สรุปผล: จากผลการศึกษาแสดงให้เห็นว่าโรคเรื้อนมีผลต่อคุณภาพชีวิตด้านผิวหนังของผู้ป่วยโดยอยู่ในระดับ ปานกลางโดยเฉพาะในกลุ่มผู้ป่วยที่เป็นโรคเรื้อนชนิดเชื้อมากและผู้ป่วยที่มีรอยโรคบริเวณใบหน้า

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Introduction

Leprosy or Hansen's disease is a chronic, gradually progressive infectious disease caused by *Mycobacterium leprae*, which is high infectivity but low pathogenicity. The main transmission route is acquired via nasal droplets. The manifestations include mainly on the skin and the peripheral nerves.¹

For the purpose of multidrug therapy (MDT) regimen, the simple classification of leprosy was established in 1981 by World Health Organization (WHO) Study Group using the degree of positivity from slit-skin smear to classify the disease as paucibacillary leprosy (PB) with bacteriological index < 2 and multibacillary leprosy (MB) with bacteriological index $2+$ or more. On the other hand, in some area which slit-skin smears are not feasible, the classification can be obtained by clinical examination as PB leprosy with one

to five skin lesions and MB leprosy with more than five skin lesions.²

Type 1 and type 2 immune-mediated leprosy reaction can affect around 30% of MB leprosy patients, most commonly during the treatment.³ Both neuritis (pain, tenderness or nerve function impairment) and silent neuritis (numbness or loss of motor function without an obvious incidence of neuritis) may occur independently with or without the reaction, and require prompt specific treatment.⁴ Delay in diagnosis, either of the disease or the reaction can increase risk of permanent nerve damage, which can progress to chronic ulcerations or various long-term deformities greatly affecting the patients' quality of life through physical and mental aspects, social stigma and many economic problems.⁵

Besides AIDS, tuberculosis, and epilepsy, leprosy is one of the chronic health-related conditions which have a strong impact on individuals, their families and public health strategy.⁶ So far, various instruments for measuring quality of life in patients with skin diseases have been developed and validated. Different methods were used such as interview, questionnaires, scales or index.⁷ From previous studies, it is well documented that leprosy had moderate to very great effect on patients' quality of life, but the data in Thailand is still lacking.⁸⁻¹²

The aim of the study was to assess the quality of life of leprosy patients in Thailand using a Thai version of Dermatology Life Quality Index (DLQI) questionnaires and evaluate other personal factors affecting the degree of patients' well-being.

Materials and methods:

This study was approved by the Siriraj Hospital Institutional Review Board (SIRB). The study design was cross-sectional descriptive study. The leprosy patients, who were literate, with an age of more than 18 years old, who attended the Hansen's clinic at Siriraj Hospital and Ratchapracha Samasai Institute between May and November 2012 were included in the study and asked to complete the DLQI questionnaires in Thai version by themselves. The demographic data, area of lesions, onset of neuritis, other associated symptoms and the amount of their families or friends who perceived about the disease were asked directly from the patient and recorded in the case record form. The

information about the type of the disease was reviewed from the medical chart and also documented in the study.

The DLQI questionnaires used in the study were pointing to the previous 7 days and were composed of 10 questions in 6 domains. The six domains consist of symptoms and feelings, daily activities, leisure, working and studying, personal relationship and treatment difficulties. Each question was short and easy to understand, so it took only a few minutes to complete. Each question consists of 3 possible scores: very much = 3, a lot = 2, a little = 1, not at all or not relevant = 0. The total DLQI score is calculated by accumulating the score of each question resulting in a minimum of 0 and a maximum of 30. The higher DLQI score depict greater impact on the quality of life among the patients. The meaning of total DLQI scores can be categorized as follows: 0-1 = no effect, 2-5 = small effect, 6-10 = moderate effect, 11-20 = very large effect, 21-31 = extremely large effect on patient's life.¹³ Finally, the Thai version of the DLQI questionnaire was formally asked for the permission from Dr. A.Y. Finlay and was reported by Kulthanan et al. as having high validity and good reliability.¹⁴

Descriptive statistics were used to describe the demographic data of the patients in this study. Pearson Chi-square test was used to test the association between two categorical variables. Multiple logistic regressions were performed to analyze the association between several patients' characteristics and DLQI score of

subgroups concurrently. All statistical analyses were done using PASW statistics 18.0 (IBM Corporation, New York, USA). A p-value < 0.05 was considered to be statistically significant.

Results

Of 75 leprosy patients from both Siriraj Hospital and Ratchapracha Samasai Institute voluntarily

answered the questionnaires and all of them completed all ten questions. Fifty-five (73.3%) of them were male and twenty (26.7%) were female. About 70% of the patients were in the age range less than 60 years, with a mean (SD) age of 46.8 (15.5) years. Most of them (65.3%) worked as laborers or farmers and 16 (21.3%) were unemployed or retired from their works. (Table 1)

Table 1 Demographic data of the study samples (n=75)

Characteristics	Number of cases	Percent (%)
Gender		
Male	55	73.3
Female	20	26.7
Age (years) - mean (SD)	46.8 (15.6)	
Less than 60	54	72.0
≥ 60	21	28.0
Employment status		
Student/officer	10	13.3
Labor	49	65.3
Unemployed	16	21.3
Type of leprosy		
Paucibacillary (PB)	15	20
Multibacillary (MB)	60	80
Site of lesions		
Facial sparing	49	65.3
Facial involvement	26	34.7
Neuritis		
No	21	28
Yes	47	62.7
Cannot remember	7	9.3

Table 2 The mean and standard deviation of DLQI scores in each question with comparison between MB and PB leprosy.

DLQI question	All cases	Type of leprosy		p-value
		PB	MB	
1.Itching/painful skin	0.89 (0.91)	0.80 (0.94)	0.92 (0.91)	0.66
2.Embarrassment	1.27 (1.12)	0.27 (0.59)	1.52 (1.08)	<0.001
3.Shopping problems	0.77 (1.03)	0.13 (0.35)	0.93 (1.09)	<0.001
4.Clothes choice	0.65 (0.97)	0.07 (0.26)	0.80 (1.02)	<0.001
5.Social activities	1.03 (1.08)	0.20 (0.56)	1.23 (1.08)	<0.001
6.Sport	0.48 (0.89)	0.07 (0.26)	0.58 (0.96)	<0.001
7.Work and study	0.76 (1.17)	0.67 (1.23)	0.78 (1.17)	0.73
8.Interpersonal problems	0.40 (0.81)	0.07(0.26)	0.48 (0.87)	0.002
9.Sexual difficulties	0.25 (0.66)	0.00 (0.00)	0.32 (0.73)	0.001
10.Treatment difficulties	0.79 (0.92)	0.60 (0.74)	0.83 (0.96)	0.383
Total scores	7.29 (5.88)	2.87 (1.81)	8.40 (6.03)	<0.001

Table 3 Patients' characteristics categorized by DLQI scores

Characteristics	DLQI score subgroups		p-value
	Low DLQI (0-6) n = 39	High DLQI (7-30) n = 36	
Gender, n (%)			0.21
Male	31 (56.4%)	24 (43.6%)	
Female	8 (40.0%)	12 (60.0%)	
Age (years) - mean (SD)	49.03 (16.13)	44.47 (14.76)	0.21
Age (years), n (%)			0.28
Less than 60	26 (48.1%)	28 (51.9%)	
≥ 60	13 (61.9%)	8 (38.1%)	
Occupation, n (%)			0.73
Student/officer	5 (50.0)	5 (50.0)	
Labor	27 (55.1)	22 (44.9)	
Unemployed	7 (43.8)	9 (56.3)	

Characteristics	DLQI score subgroups		p-value
	Low DLQI (0-6) n = 39	High DLQI (7-30) n = 36	
Type of leprosy, n (%)			<0.001
Paucibacillary (PB)	14 (93.3%)	1 (6.7%)	
Multibacillary (MB)	25 (41.7%)	35 (58.3%)	
Site of lesions, n (%)			0.002
Facial sparing	32 (65.3%)	17 (34.7%)	
Facial involvement	7 (26.9%)	19 (73.1%)	
Neuritis, n (%)			0.18
No	14 (66.7%)	7 (33.3%)	
Yes	23 (48.9%)	24 (51.1%)	
Pain or numbness, n (%)			0.80
No	13 (54.2%)	11 (45.8%)	
Yes	26 (51.0%)	25 (49.0%)	

According to the classification of leprosy, 60 (80%) of the cases were diagnosed as MB leprosy. Forty-seven (62.7%) patients can recognize their previous neuritis, and most of these cases (68.1%) experienced neuritis symptoms before the diagnosis. About 35% of the patients had facial-involved lesions. Only 36% of the patients had informed their friends about the illness, with the mean (SD) of 2.60 (5.64). On the other hand, 69.3% of them told their families about the disease with the mean (SD) of 2.73 (2.77).

The mean (SD) of total DLQI scores were 7.29 (5.88) with a median of 6 and a range of 0-29. From 10 questions, the highest mean scores were observed in the second question concerning the patients' embarrassment with a mean (SD) of 1.27 (1.12), followed by the

question about social activities with a mean (SD) of 1.03 (1.08). And the lowest mean scores were in the domain of sexual difficulties. From table 2, the mean (SD) of DLQI scores in each questions when compared between MB and PB leprosy, were significantly higher in MB group regarding almost every questions ($p < 0.01$) except the items of itching/painful ($p = 0.66$), work and school ($p = 0.73$) and treatment ($p = 0.38$). The total DLQI scores in MB group were also higher than PB group ($p = 0.001$).

Nonetheless, there was no significant relationship between age ($p = 0.25$), gender ($p = 0.56$), employment status ($p = 0.90$) or neuritis symptoms ($p = 0.30$) with total DLQI scores. Only in the fifth question concerning

the social activities, the scores were significantly higher in the cases who had encountered neuritis ($p = 0.049$).

Table 3 presents characteristics of the patients grouped by the median of total DLQI scores as low (0-6) and high (7-30) DLQI score subgroups. High DLQI score was associated with the group of MB leprosy ($p < 0.001$) and facial involvement of the lesions ($p = 0.002$)

From multiple logistic regressions (Table 4), the results correlate the same way. The patients with MB leprosy had a significantly higher DLQI score than the PB group with adjusted odds ratio of 13.83 (95% CI OR 1.65-115.58, $p = 0.015$). And the patients with facial lesions also scored significantly higher than those without facial involvement with adjusted odds ratio of 3.54 (95% CI OR 1.18-10.68, $p = 0.025$).

Table 4 Multiple logistic regression analysis of patients' characteristics related to DLQI score subgroups

Characteristics	Adjusted OR	95% CI of OR	p-value
Type of leprosy, n (%)			
Paucibacillary (PB)	1		
Multibacillary (MB)	13.83	1.65-115.58	0.015
Site of lesions, n (%)			
Facial sparing	1		
Facial involvement	3.54	1.18-10.68	0.025

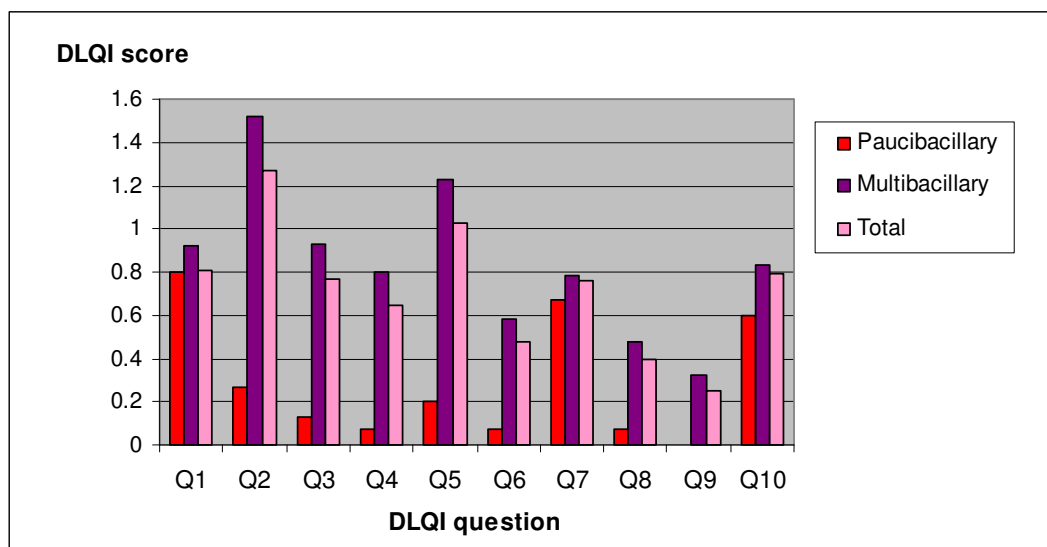


Figure 1 The mean DLQI scores of each question

Discussion

Data from the present study demonstrated that male was the predominant gender of leprosy patients in our country which revealed the same outcome as previous studies claiming male as one of a risk factor of Hansen's disease.² There was no significant difference of the DLQI scores between both genders in our study ($p = 0.56$), on the contrary of the study by Budel et al. which showed the statistically significant differences between the scores of both sexes.¹⁰ In a previous study in Brazil, the mean (SD) of total DLQI score was 10.23 (7.79), the PB group was 9.00 (8.06) and the MB group was 10.80 (7.88) respectively¹⁰, which were all higher than the results in the current study. It is probably due to the individual social culture regarding sympathy and the way of thinking about the disease which lead to the effect of the patients' quality of life.

The patients in MB group scored significantly higher than those in PB group in almost all aspects. Except for the 2 questions about itching/pain and working/studying. These findings could be explained by the lesional anesthesia without pruritus in lepromatous skin involvement¹, and most of our cases did not have deformity or disability from the disease to prevent their working or studying performances.

Additionally, the mean DLQI scores in facial involvement group were significantly higher than those without facial lesions. This result correlated with the highest mean DLQI score (1.27) observed in embarrassment domain in recent study, and the lowest

is sexual difficulties with the mean score of 0.25. In a similar way to the result from Kulthanan et al. studied patients with general skin diseases, the highest and lowest DLQI scores were observed in the same domain as ours.¹⁴ Earlier, Kulthanan et al. had posited that this phenomenon may result from the culture of Asians who feel uncomfortable talking about sexual relationships.¹⁵

Neuritis or silent neuropathy can occur before, during or after the treatment. But the most common is during the treatment.⁴ Most of the cases with neuritis in this study experienced neuritis symptoms before the diagnosis. The result may indicate that the strategy for providing early diagnosis of the disease in Thailand is still ineffective. And the mean DLQI scores in neuritis group were not significantly higher than those without neuritis, perhaps because the symptoms of neuritis may have abated by the time of data collection.

When we compared the mean of DLQI score of leprosy patients in our study with other skin diseases in the same ethnic group such as acne (10.6), psoriasis (12.9), and vitiligo (8.8), it surprisingly showed that the scores of leprosy patients were lower. It is probably from the natural history of the disease that is slowly progressive and becomes almost stable after specific MDT regimens.

The leprosy control program is still important to prevent disabilities. Widely provision of proper education about the transmission and natural history of the disease is needed for the patients, health care personnel and also the general population to improve

the mental health of the leprosy patients, leading to better quality of life. Furthermore, using this questionnaire can be applied in the future to re-evaluate and improve the efficacy of the leprosy control program.

Conclusion

The DLQI score of leprosy patients in this study indicates the moderate impact of the disease on quality of life, especially in those with multibacillary type and those with lesions on the face. To our knowledge, this study is the first study on the dermatology quality of life in the patients with leprosy in Thailand. Dermatologists as well as general physicians retain the main responsibility for taking care of these patients. It must be emphasized that a holistic approach to each patient needs to be mentioned regarding their quality of life.

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