

Quality of life in patients with erythema nodosum leprosum in Kuala Lumpur, Malaysia

Felix B. Yap^{1,2}, Sze T. Kiung³, Jeffrey B. Yap⁴

¹Department of Medicine, Faculty of Medicine and Health Sciences, Universiti Tunku Abdul Rahman, Sungai Long Campus, ⁴Department of Surveying, Lee Kong Chian Faculty of Engineering and Science, Universiti Tunku Abdul Rahman, Sungai Long Campus, Selangor DE, Departments of ²Dermatology and ³Anaesthesiology and Intensive Care, Hospital Kuala Lumpur, Jalan Pahang, Kuala Lumpur, Malaysia

ABSTRACT

Background: There is a paucity of data on quality of life issues in patients with leprosy suffering from erythema nodosum leprosum (ENL). Thus, we aim to study the effect of ENL on quality of life. **Materials and Methods:** This cross-sectional study was conducted in Hansen's Clinic, Hospital Kuala Lumpur between January 2010 and December 2013 among patients with multibacillary leprosy using the Dermatology Life Quality Index (DLQI). **Results:** A total of 153 patients participated with 31.4% suffering from ENL. The mean age at presentation was 40.5 ± 16.49 years. The mean DLQI was 7.1 ± 3.72 . Patients with ENL were younger (mean age 36.5 vs. 42.4, $P = 0.026$), had higher mean bacteriologic index (4.3 vs. 3.8, $P = 0.004$), had physical deformities (47.9% vs. 31.4%, $P = 0.049$), and had higher mean DLQI score (9.1 vs. 6.2, $P < 0.001$). All the DLQI domains were higher in patients suffering from ENL except the treatment domain. Symptoms and feeling was the domain with the largest effect followed by daily activities and leisure. Personal relationship had the lowest effect. **Conclusion:** Quality of life impairment in patients with leprosy in Malaysia is moderate, with larger effect among patients with ENL. The impairment in ENL is comparable to itchy skin conditions such as urticarial and is worse than chronic skin disease such as psoriasis. Thus, it is essential that management of leprosy incorporate quality of life issues.

Key words: Dermatology Life Quality Index, erythema nodosum leprosum, leprosy, Malaysia, quality of life

INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* affecting mainly the skin and peripheral nerves. Management of this condition is often complicated by leprosy reactions. Type 2 leprosy reaction or erythema nodosum leprosum (ENL) is a humoral immunological reaction that leads to formation of nodules on the skin and inflammation of the nerves and internal organs. The incidence of ENL in 11 field studies conducted in various countries ranged between 0.2 and 4.6%, with an average of 1.2%.^[1] In the hospital setting, the incidence of ENL varied between 0.2 and 37%, with an average of 13.7% based on 28 studies.^[1] This occurrence of ENL correlates directly with bacteriologic index (BI) and increases significantly with pregnancy and lactation.^[1]

Leprosy is still seen in Malaysia, although being eliminated as a public health problem, with reported cases < 1 in 10000 population since 1994.^[2,3] It is seen mainly in East Malaysia and Kuala Lumpur.^[2] In Kuala Lumpur, leprosy is

increasingly seen among foreign workers, mainly from Indonesia. The prevalence of ENL among multibacillary leprosy patients is reported to be 40% in Malaysia.^[4] Despite multiple publications on ENL, especially on its risk factors, there is scarcity of data on quality of life issues among leprosy patients with ENL. Thus, we aim to study the effect of ENL on the quality of life among patients with multibacillary leprosy.

MATERIALS AND METHODS

This is a cross-sectional study that was conducted in Hansen's Clinic, Hospital Kuala Lumpur, between January 2010 and December 2013. All

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

Cite this article as: Yap FB, Kiung ST, Yap JB. Quality of life in patients with erythema nodosum leprosum in Kuala Lumpur, Malaysia. Indian Dermatol Online J 2016;7:255-8.

Access this article online

Website: www.idoj.in

DOI: 10.4103/2229-5178.185495

Quick Response Code:



Address for correspondence:

Dr. Felix B. Yap,
Department of
Medicine, Faculty of
Medicine and Health
Sciences, Universiti
Tunku Abdul Rahman,
Sungai Long Campus,
Jalan Sungai Long,
43000 Kajang,
Selangor DE, Malaysia.
E-mail: woodzlamp@
yahoo.com

the patients with leprosy attending the clinic were invited to participate in the study.

The inclusion criteria for the study were adult patients with leprosy, older than 18 years of age, diagnosed to have multibacillary leprosy (MBL) based on slit skin smear examination, and been on treatment for at least 3 months. The exclusion criteria were patients diagnosed to have paucibacillary leprosy and Type 1 leprosy reaction.

Eligible patients were invited to complete a standardized case report form and the Dermatology Life Quality Index (DLQI) questionnaire. The case report form collected data on demographics and clinical characteristics of the patients including the bacteriologic index (BI) and morphological index (MI) at initial presentation. The DLQI questionnaire was used to assess the quality of life impairment.

DLQI is a quality of life tool for adults consisting of 10 multiple choice questions, each with a score of 0–3.^[5] The sum of the scores determine the quality of life impairment with higher scores denoting higher impairment. The score of 0–1 denote no effect in quality of life, 2–5 denotes small effect, 6–10 denotes moderate effect, 11–20 denotes large effect, and 21–30 denotes extremely large effect. The permission to use DLQI was granted by Professor Finlay.^[5]

Data collected were analyzed using Statistical Package for the Social Sciences version 13 (SPSS Inc., Chicago, IL, USA). Categorical data were analyzed using Chi-square test and presented as number (percentages). Continuous data were analyzed using student *t* test and presented as mean ± standard deviation. Level of significance was set at *P* < 0.05.

RESULTS

A total of 153 patients completed the DLQI questionnaire. Of this, 48 (31.4%) patients had ENL. Majority of the patients (74.5%) were males. There were 84 Malaysian (55.5%) and 69 (34.5%) foreigners, of which majority (92.8%) were Indonesians. The mean age at presentation was 40.5 ± 16.49 years. The mean BI at presentation was 3.9 ± 1.12, and the mean MI at presentation was 3.4 ± 7.64. Physical deformities were seen in 36.6% of patients.

The mean DLQI was 7.1 ± 3.72, ranging between 1 and 21. There were 7.8% of patients who did not have impairment in their quality of life. Most (50.3%) had moderate impairment with 22.2% having small impairment, 19.0% having large impairment, and only 0.7% having extremely large impairment.

Table 1 shows the comparison of patients with ENL and those without. Patients with ENL tend to be younger (mean age 36.5 vs. 42.4, *P* = 0.026), had higher BI (mean BI 4.3 vs. 3.8, *P* = 0.004), had physical deformities or disabilities (47.9% vs. 31.4%, *P* = 0.049), and had more impairment in their quality of life (mean DLQI score 9.1 vs. 6.2, *P* < 0.001). All the 48 patients with ENL had some impairment in their quality of life [Table 2]. These patients reported significantly larger effects on their quality of life due to their disease compared to patients without ENL (*P* = 0.002). Patients with physical deformities or disabilities had higher impairment in their DLQI score (8.5 ± 3.73 vs. 6.4 ± 3.50, *P* = 0.01). Among patients with ENL, the physical disabilities tend to cause a higher mean DLQI score albeit not statistically significant (9.9 ± 4.23 vs. 8.3 ± 3.12, *P* = 0.133). In those without ENL, the physical deformities caused a significantly higher quality of life impairment (7.4 ± 3.00 vs. 5.3 ± 3.14, *P* = 0.013).

Patients with ENL had significantly higher scores in all the questions in the DLQI questionnaire except Question 10 on treatment [Table 3]. They had larger effects in all domains of DLQI except treatment domain. Symptoms and feelings was the most affected domain followed by daily activities. The least affected were personal relationships and treatment.

Table 1: Comparison of demographics, clinical characteristics, and Dermatology Life Quality Index among patients with and without erythema nodosum leprosum

| Variables | With ENL (n=48) | Without ENL (n=105) | P value |
|----------------------------------|-----------------|---------------------|---------|
| Mean age at presentation (years) | 36.5±14.16 | 42.4±17.19 | 0.026 |
| Gender | | | |
| Male | 36 (75.0%) | 78 (74.3%) | 0.925 |
| Female | 12 (25.0%) | 27 (25.7%) | |
| Nationality | | | |
| Malaysian | 23 (47.9%) | 61 (58.1%) | 0.240 |
| Foreigner | 25 (52.1%) | 44 (41.9%) | |
| Mean pretreatment MI | 2.8±1.34 | 3.6±9.18 | 0.540 |
| Mean pretreatment BI | 4.3±0.89 | 3.8±1.19 | 0.004 |
| Mean DLQI score | 9.1±3.74 | 6.2±3.36 | <0.001 |
| Presence of physical deformities | 23 (47.9%) | 33 (31.4%) | 0.049 |

Table 2: Quality of life impairment among patients with and without erythema nodosum leprosum

| Variables | With ENL (n=48) | Without ENL (n=105) | P value |
|------------------------|-----------------|---------------------|---------|
| No effect | 0 | 12 (11.4%) | 0.002 |
| Small effect | 6 (12.5%) | 28 (26.7%) | |
| Moderate effect | 26 (54.2%) | 51 (48.6%) | |
| Large effect | 15 (31.2%) | 14 (13.3%) | |
| Extremely large effect | 1 (2.1%) | 0 | |

Table 3: Comparison of Dermatology Life Quality Index scores among patients with and without erythema nodosum leprosum

| Variables | With ENL (n=48) | Without ENL (n=105) | P value |
|-----------------------------------|--------------------|------------------------|---------|
| Symptoms and feelings (Q1 and Q2) | 3.2±0.72 | 2.6±0.90 | <0.001 |
| Daily activities (Q3 and Q4) | 1.8±0.98 | 1.3±0.86 | 0.001 |
| Leisure (Q5 and Q6) | 1.6±1.16 | 0.9±1.04 | <0.001 |
| Work and school (Q7) | 1.2±0.81 | 0.8±0.69 | 0.002 |
| Personal relationship (Q8 and Q9) | 0.8±1.00 | 0.2±0.53 | 0.001 |
| Treatment (Q10) | 0.4±0.65 | 0.4±0.55 | 0.930 |

DISCUSSION

Patients with multibacillary leprosy in Malaysia have moderate impairment in their quality of life, as reflected by the mean DLQI of 7.1. This mean score is significantly lower than the mean scores of patients with multibacillary leprosy in Brazil and China.^[6-8] This might be due to the stoic nature of patients from Malaysia.^[9] The upbringing of Malaysians discourages public affection of feelings. Similarly, Indonesians are also culturally related to Malaysians. Hence, it is not surprising to note that the personal relationship domain in the DLQI has the lowest score because this issue is a taboo in Southeast Asia.

Patients with leprosy have more impairment in their quality of life compared to local patients with chronic skin diseases i.e., psoriasis (mean DLQI 5.8), acne (mean DLQI 4.1), and vitiligo (mean DLQI 6.4).^[9-11] Those who have ENL with a mean DLQI of 9.1 have comparable quality of life impairment to pruritic skin diseases such as urticaria (mean DLQI 9.9), hand eczema (mean DLQI 9.5), and scabies (mean DLQI 10.0).^[12-14]

Studies in Brazil using the World Health Organisation Quality of Life (WHOQOL-bref) questionnaire showed that patients with leprosy reactions tend to have more severe impairment in the physical domain.^[15,16] This domain consists of pain and discomfort, dependency on medication or treatment, energy and fatigue, sleep and rest, mobility, daily activities, and work capacity. Professional activities and leisure were the worst affected.^[15] Those with physical disability tend to have more impairment in their quality of life.^[16] Using DLQI, a different tool compared to WHOQOL-bref, we noticed that the worst affected domain was symptoms and feelings followed by daily activities and leisure. These two DLQI domains measure physical symptoms, feelings, and daily activities, which are a part of the parameters included in the physical domain of WHOQOL-bref. Patients with ENL tend to be more symptomatic.^[17] The nodules in ENL are painful and irritating. Some also develop fever, weight loss, and discomfort.^[18] This reactional state causes inflammation of various organ systems and frequently leads to

functional activity limitation. Functional activity limitation lowers the quality of life. This can be seen in the physical domain of WHOQOL-bref, which was significantly lower in those with very severe functional limitation compared to those without this limitation in a Brazilian study (25 vs. 71.4, $P < 0.001$).^[16] This disability also frequently limits daily activities.

Patients with ENL reported a decrease in leisure and daily social activities compared to patients without ENL. This might be related to the pain and discomfort from the leprosy reaction as well as the social isolation from this condition. The social isolation and stigma also leads to poor personal relationship with others. Depression, anxiety, and stigma are well documented in patients with leprosy. The psychosocial issue not only leads to problems with relationship but also employment opportunities, job security social status, and personal dignity.^[19] This is worsened with the presence of handicap and disability, more commonly seen among patients with leprosy reaction.^[20]

It is interesting to note that there is no statistical difference in the treatment domain of DLQI between those with and without ENL. It has been postulated that patients with ENL would be more troubled by the medications and treatment of the condition. Patients with ENL would need to take more medications in the form of immunosuppression and have to endure more frequent follow up visits to the hospital. The side effects of the medications are also more disabling. One possible reason for this interesting finding might be that a higher proportion of ENL patients were foreigners, and because treatment of communicable diseases in Malaysia is free of charge, they were happy with the provided treatment. In a systematic review, it was noted that compliance to medication was better with lower medication cost and employment status.^[21]

It is imperative that the management of patients with leprosy should not only focus on clinical improvement but also on the quality of life issues. The treating clinicians must address the physical and psychosocial issues faced by these patients in order to improve their quality of life. This is even more so in patients with ENL. Assessing the quality of life in the clinic setting using validated tools such as DLQI will help clinicians better understand their patients and manage them in a more holistic manner.

In conclusion, quality of life impairment in patients with leprosy is moderate, with larger effect in patients with ENL. The impairment in ENL is comparable to itchy skin conditions such as urticaria, hand eczema, and scabies and is worse than chronic skin diseases such as psoriasis, acne, and vitiligo. Patients with ENL had more impairment in all the domains of DLQI except the treatment domain. Thus, it is essential that the management of leprosy incorporates quality of life issues, especially so in patients with ENL.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Voorend CG, Post EB. A systematic review on epidemiological data of erythema nodosum leprosum, a type 2 leprosy reaction. *PLoS Negl Trop Dis* 2013;7:e2440.
2. Yap FB. Leprosy in Sarawak, East Malaysian Borneo. *Scand J Infect Dis* 2009;41:320.
3. Bin Yap FB. Pediatric leprosy in Sarawak, Malaysia. *Pediatr Infect Dis J* 2009;28:933-4.
4. Yap FB. Clinical characteristics predicting erythema nodosum leprosum (ENL) among patients with multibacillary leprosy (MBL) in Sarawak. *Asian Pac J Trop Med* 2009;2:66-70.
5. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)—a simple practical measure for routine clinical use. *Clin Exp Dermatol* 1994;19:210-6.
6. An JG, Ma JH, Xiao SX, Xiao SB, Yang F. Quality of life in patients with lepromatous leprosy in China. *J Eur Acad Dermatol Venereol* 2010;24:827-32.
7. Budel AR, Raymundo AR, Costa CF, Gerhardt C, Pedri LE. Profile of patients affected by Hansen's disease seen at the Outpatient Clinic of Dermatology at Hospital Evangélico de Curitiba. *An Bras Dermatol* 2011;86:942-6.
8. Proto RS, Machado Filho CD, Rehder JR, Paixão MP, Angelucci RI. Quality of life: A comparative analysis between patients in the Amazon region and patients in Santo André in the ABC region of São Paulo, Brazil. *An Bras Dermatol* 2010;85:939-41.
9. Yap FB. Psoriasis among Sarawakian natives in a tertiary skin centre in Sarawak. *Australas J Dermatol* 2010;51:210-1.
10. Yap FB. The impact of acne vulgaris on the quality of life in Sarawak, Malaysia. *J Saudi Soc Dermatol Dermatol Surg* 2012;16:57-60.
11. Wong SM, Baba R. Quality of life among Malaysian patients with vitiligo. *Int J Dermatol* 2012;51:158-61.
12. Liu JB, Yao MZ, Si AL, Xiong LK, Zhou H. Life quality of Chinese patients with chronic urticaria as assessed by the dermatology life quality index. *J Eur Acad Dermatol Venereol* 2012;26:1252-7.
13. Charan UP, Peter CV, Pulimood SA. Impact of hand eczema severity on quality of life. *Indian Dermatol Online J* 2013;4:102-5.
14. Jin-Gang A, Sheng-Xian X, Sheng-Bin X, Jun-Min W, Song-Mei G, Ying-Ying D, *et al.* Quality of life of patients with scabies. *J Eur Acad Dermatol Venereol* 2010;24:1187-91.
15. Costa MD, Terra Fde S, Costa RD, Lyon S, Costa AM, Antunes CM. Assessment of quality of life of patients with leprosy reactional states treated in a dermatology reference center. *An Bras Dermatol* 2012;87:26-35.
16. Santos VS, Oliveira LS, Castro FD, Gois-Santos VT, Lemos LM, Ribeiro Mdo C, *et al.* Functional activity limitation and quality of life of leprosy cases in an endemic area in northeastern Brazil. *PLoS Negl Trop Dis* 2015;9:e0003900.
17. Kamath S, Vaccaro SA, Rea TH, Ochoa MT. Recognizing and managing the immunologic reactions in leprosy. *J Am Acad Dermatol* 2014;71:795-803.
18. Cuevas J, Rodríguez-Peralto JL, Carillo R, Contreras F. Erythema nodosum leprosum: Reactional leprosy. *Semin Cutan Med Surg* 2007;26:126-30.
19. Singh GP. Psychosocial aspect of Hansen's disease (leprosy). *Indian Dermatol Online J* 2012;3:166-70.
20. Van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, *et al.* Disability in people affected by leprosy: The role of impairment, activity, social participation, stigma and discrimination. *Glob Health Action* 2012;5.
21. Mathes T, Jaschinski T, Pieper D. Adherence influencing factors—a systematic review of systematic reviews. *Arch Public Health* 2014;72:37.