ORIGINAL ARTICLE

Quality of life of leprosy patients in Sabah

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ABSTRACT

Objective: To determine the Dermatology Life Quality Index (DLQI) among the subtypes of leprosy and to examine correlation with deformity and lepra reactions.

Methods: This was a cross-sectional study done at Dermatology Outpatient Clinic, Queen Elizabeth Hospital and two health clinics in Kota Kinabalu between 1st April 2019 and 30th November 2019. A standardised case report form was formulated to collect the demographic data and disease profile of the leprosy patients. The quality of life (QoL) was assessed using Dermatology Life Quality Index (DLQI) questionnaire.

Results: A total of 54 patients were included with a male to female ratio of 2.4:1 (38 males and 16 females). The mean DLQI score was 8.31±6.15. The difference between the mean DLQI scores among the leprosy subtypes was not significant. The most affected domain was symptoms and feeling followed by daily activities and leisure. Twenty-one patients (38.9%) had facial deformity and they were found to have significantly higher DLQI score. WHO grade 1 and 2 disability were observed in 37 patients (68.5%) with higher DLQI score compared to those without any disability. More than half of patients with MB leprosy (52.2%) developed lepra reactions but the difference of mean DLQI scores were not significant.

Conclusions: Leprosy-related disabilities may predispose patients to develop psychosocial problems which may have negative impact on QoL. Thus, periodic assessment of QoL should be incorporated into the management of leprosy patients

INTRODUCTION

Leprosy, also known as Hansen's disease, is a chronic granulomatous infectious disease caused by Mycobacterium leprae. It can affect the skin, peripheral nerves, nasal mucosa and eyes. Leprosy, if left untreated, may lead to permanent skin and nerve damage, limb deformity and functional disability.[1] In Malaysia, although leprosy has been eliminated as a public health problem since 1994, new cases are still being reported annually, mainly in Sabah and Selangor.[2] Sabah is the second largest state in Malaysia with an area of 73,904 km^2 and a population of 3.9 million.[3] Among the 214 new cases detected in 2017, Sabah reported 72 cases (33.6%), followed by Selangor 34 cases (15.9%); 2.8% had WHO grade 2 disability at the time of diagnosis.[4] The number of leprosy cases was more frequent in suburban and rural areas with substantial numbers of vulnerable migrant patients.

The implementation of multidrug therapy throughout the world has been effective against leprosy and it shows good prospects for the management. Early case detection and adherence to therapy are both equally important. However, if the treatment is delayed, patients with leprosy may progress to develop nerve damage and disability. The leprosy-related disabilities may affect the physical and emotional wellbeing of patients eventually leading to psychosocial and economic burden with negative impact on the quality of life (QoL).

There is insufficient information on the QoL among leprosy patients in South East Asia. Hence this study is aimed to assess the QoL of different subtypes of leprosy and its correlation with deformity and lepra reactions.

MATERIALS AND METHODS

This was a cross-sectional study done at Dermatology Outpatient Clinic of the Queen Elizabeth Hospital (QEH) and two health clinics in Kota Kinabalu (Menggatal and Putatan Health Clinic) between 1st April 2019 and 30th November 2019. All patients with leprosy were requested to participate in this study. The QEH is the referral centre for the management of leprosy with complications for Sabah and Labuan.

The inclusion criteria were patients with leprosy age 12 years and above who had given consent. Diagnosis was made based on clinical examination and slit skin smear, as well as histopathological examination in selected cases. The exclusion criteria were patients with the aged below 12 years and those with other active dermatoses.

A standardised case report form was formulated to collect the demographic data and disease profile of the participants. The presence of lepra reaction, the World Health Organization (WHO) disability grading and facial deformity were recorded. WHO grade 1 disability (G1D) includes the presence of anesthesia of the hands and feet or presence of eye problems due to leprosy, but not severely affected with visual acuity of at least 6/60 or able to count fingers at 6 metres. WHO grade 2 disability (G2D) is defined as visible deformity at the hands and feet or severe visual impairment.[5] Facial deformity includes saddle nose, external ear deformity, madarosis and eye deformity such as lagophthalmos.

The QoL was assessed using Dermatology Life Quality Index (DLQI) questionnaire which was created by Professor Finlay and permission to use it was granted.[6] DLQI questionnaire is a user-friendly and validated tool commonly used which demonstrated satisfactory validity and reliability in assessing the QoL of patients. It is designed for use in children and

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adults comprising of 10 multiple choice questions which is usually completed in one to two minutes. The domains assessed by the DLQI questionnaire are physical symptoms and feelings (question 1 and 2), daily activities (question 3 and 4), leisure (question 5 and 6), school or work (question 7), interpersonal relationship (question 8 and 9) and treatment (question 10). The DLQI score is calculated by summing the score of each question resulting in a maximum score of 30 and a minimum of 0. The higher the score, the more impaired the QoL. The interpretation of DLQI score is: 0-1= no effect on patient's life, 2-5=small effect on the life of patients, 6-10=moderate, 11-20=very large and 21-30= extremely large.

Data collected were analysed using Statistical Package for the Social Sciences (SPSS) version 24. Categorical data were analysed using Chi-square test or Fischer Exact test and presented as number (percentage). Continuous data were analysed using t-test and Mann-Whitney test. For more than 3 groups of continuous data, the data were analysed using One-Way ANOVA or Kruskal Wallis test. The analysed data were presented as mean ± standard deviation or median and interquartile range. Level of significance was set at $p<0.05$.

RESULTS

A total of 54 patients participated in this study with 38 (70.4%) males and 16 (29.6%) females. There were 37 (68.5%) Malaysians and 17 (31.5%) foreigners. Ten patients were recruited from the health clinics. The mean age at presentation was 37.96±16.05 years. A total of 18 patients (33.3%) had history of contact in the family. The mean bacteriological index (BI) and morphological index (MI) at presentation were 2.78±1.66 and 1.51±2.31 respectively. Table I shows the demographic characteristics of leprosy patients. Of the 54 patients, 46 (85.2%) had multibacillary (MB) leprosy and 8 (14.8%) had paucibacillary (PB) leprosy. Half of the MB leprosy (50%) were borderline lepromatous and 7 out of 8 PB leprosy (87.5%) were borderline tuberculoid. Table II shows the clinical characteristics of leprosy patients.

The mean time interval between symptoms onset and diagnosis of leprosy was 20.62±22.57 months. The mean DLQI score was 8.31±6.15, ranging between 0 and 23. There was no significant difference between the mean DLQI scores of MB and PB leprosy patients (8.57±6.27 vs. 6.88±5.51, p=0.478). The difference between the mean DLQI scores among leprosy subtypes was also not statistically significant. Four out of 8 patients (50%) with PB had moderate to extremely large impairment in QoL. Among patients with MB leprosy, the QoL of as many as 30 patients (65.2%) was moderate to extremely largely impaired. The most affected domain was symptoms & feelings followed by daily activities and leisure in both groups. Table III shows the association between DLQI scores and the types of leprosy.

Twenty-one patients (38.9%) had facial deformity. Two-third of them were diagnosed with lepromatous leprosy while the others having borderline lepromatous leprosy. Those with facial deformity were found to have significantly higher DLQI score compared to those without facial deformity (10.57±6.01 vs 6.88±5.87, p=0.030). WHO grade 1 and 2 disability were observed in 37 patients (68.5%). They had higher DLQI scores compared to those without any disability [median (IQR) 9.0 (10) vs. 3.0 (9), p=0.007]. Table IV shows the association between DLQI score and facial deformity & WHO disability grading respectively. Significantly more patients with WHO disability (both grade 1 and 2) reported their QoL to be moderate to extremely largely affected [75.6% (28 of 37 patients vs 35.3% (6 of 17 patients), p=0.013].

More than half of the patients with MB leprosy (24 out of 46, 52.2%) developed lepra reactions, with 7 patients (15.2%) and 17 patients (37.0%) having type 1 and type 2 reaction respectively. Patients with type 2 lepra reaction were found to have significantly higher BI compared to patients with type 1 lepra reaction and patients without any reaction [median (IQR) 4.20 (2.09) vs. 2.55 (1.64) vs. 2.50 (3.83), p=0.030]. However, the difference between the mean DLQI scores among patients with and without lepra reaction was not statistically significant.

DISCUSSION

Leprosy, particularly multibacillary leprosy, may be associated with facial deformity, neuropathic pain and physical disability.[7] Facial deformity can have significant psychosocial implications, including altered body image, poor self-esteem and social avoidance, resulting in impaired social interaction and negative self-perception. Leprosy causes damage that goes beyond the discomfort related to physical impairment; eventually these patients will suffer from social stigma, discrimination and low QoL.[8]

The QoL among patients with leprosy is moderately impaired as evidenced by the mean DLQI score of 8.31±6.15. Our scores are similar to a study in India where the reported mean score was 8.48±5.48.[9] However our mean score is slightly lower than that of the leprosy patients in Egypt (11.58) and Brazil (10.23).[10] Interestingly our lepromatous leprosy (LL) patients had much lower DLQI score compared to the LL patients in China (18.78).[11] This may be due to the lower proportion of WHO grade 2 disability among the LL patients in our cohort. Majority of the patients with PB leprosy did not have QoL impairment in Brazil,[12] in contrast to our study where half of PB leprosy patients had moderate to extremely large impairment in QoL. This could be due to the presence of nerve damage and lepra reactions among our PB patients.

The new case detection rate of leprosy in Malaysia was 0.57 per 100,000 however it was 1.6 per 100,000 in Sabah which was higher than the national indicator (<1 per 100,000).13 The higher burden of leprosy in Sabah compared to other states in Malaysia might be due to unique socioeconomical situation of Sabah and its less developed topography. Nearly a third of the population in Sabah comprises of non-Malaysians.[13] The geographical location of Sabah in South East Asia with its extensive and porous borders makes it accessible from neighbouring countries thus resulting in higher burden of leprosy.[14] In addition, Sabah has the highest poverty rate among all the states in Malaysia.[15] Late recognition of leprosy is often associated with inadequate knowledge about the disease and lack of awareness not only

Table I: Demographic characteristics of leprosy patients, n= 54

Variables	n (%)
Gender	
Male	38 (70.4)
Female	16 (29.6)
Marital status	
Married	32 (59.3)
Single	19 (35.2)
Divorced	3 (5.6)
Nationality	
Malaysian	37 (68.5)
Non-Malaysian	17 (31.5)
Family History	
Present	18 (33.3)
Absent	36 (66.7)

Table II: Clinical characteristics of 54 leprosy patients

Variables	n (%)
WHO Classification	
Multibacillary (MB)	46 (85.2)
Paucibacillary (PB)	8 (14.8)
Ridley-Jopling Classification	
Lepromatous (LL)	20 (37.0)
Borderline Lepromatous (BL)	23 (42.6)
Midborderline (BB)	3 (5.6)
Borderline Tuberculoid (BT)	7 (13.0)
Tuberculoid (TT)	1 (1.9)
Facial deformity	
Present	21 (38.9)
Absent	33 (61.1)
WHO Disability Grading	
Grade 0	17 (31.5)
Grade 1	17 (31.5)
Grade 2	20 (37.0)
Lepra reactions	
No reaction	29 (53.7)
Type 1 reaction	8 (14.8)
Type 2 reaction	17 (31.5)

Table III : Association between types & subtypes of leprosy and DLQI score

WHO Classification	**DLQI score Mean (SD)**
Multibacillary (MB)	8.57 (6.27)
Paucibacillary (PB)	6.88 (5.51)
Ridley-Jopling Classification	**DLQI score Median (IQR)**
Lepromatous (LL)	6.5 (10.0)
Borderline Lepromatous (BL)	8.0 (10.0)
Midborderline (BB)	13.0 (-)
Borderline Tuberculoid (BT)	5.0 (11.0)
Tuberculoid (TT)	-

Table IV : Association between DLQI score and facial deformity & WHO disability grading

Facial Deformity	**DLQI score Mean (SD)**
Present	10.57 (6.01)
Absent	6.88 (5.87)
WHO Disability Grading	**DLQI score Median (IQR)**
Grade 1 & 2	9.0 (10)
Grade 0	3.0 (9)

among patients but also health-care workers and community members. This lack of knowledge on leprosy and persistence of leprosy-related stigma may reflect a lack of dissemination of correct information in the community.[16] G2D were observed in 20 (37%) patients and this is much higher than previously reported, 8.6% in India, 17.1 % in Brazil and 20.66% in Egypt.[17-19] This could be due to the lack of education and delay in diagnosis and treatment, as shown by the prolonged time interval between the onset of symptoms and diagnosis in our study. Misdiagnosis of leprosy as other similar cutaneous diseases by primary care personnel could be another contributing factor to the delay in diagnosis leading to G2D. This may be due to the limited experience and poor confidence level among the primary care doctors.[20] A study done in a tertiary referral centre in Kuala Lumpur, the capital of Malaysia reported misdiagnosis in 44.4% of the cases in primary care setting.[21] G2D can also develop after patients was diagnosed, while on or after completion of treatment due to reactions.[22]

Patients with MB leprosy experienced more impairment in QoL compared to patients with chronic skin diseases, such as acne vulgaris (mean DLQI 4.1), chronic urticaria (mean DLQI 4.8), vitiligo (mean DLQI 5.2), psoriasis (mean DLQI 5.8) and atopic dermatitis (mean DLQI 6.1).[23-26] The QoL impairment was significantly larger among leprosy patients with facial deformity and grade 1 & 2 disabilities. Govindharaj, P et al from India using WHO Quality of Life questionnaire (WHOQOL-BREF) reported significant differences in all the domains (physical health, psychosocial health, social relationship and environment) among leprosy patients with or without disability.[27]

A study conducted by Santos et al. in Brazil also using the WHOQOL-BREF questionnaire showed that leprosy patients with functional activity limitations (FALs) were associated with low QoL. They tend to have more severe impairment in the physical and environmental domains. The FALs which was determined by Screening of Activity Limitation and Safety Awareness Scale (SALSA) were found to be associated with the presence of disability. The SALSA score was higher in MB leprosy indicating lower QoL.[28] However we found no significant difference in the DLQI score among our MB patients compared to PB patients probably due to the small number of patients.

Leprosy patients had moderate impairment in their QoL, with larger effect among patients with lepra reactions, especially type 2 reaction, also known as erythema nodosum leprosum (ENL). A previous study done in Malaysia found MB leprosy patients with ENL had a mean DLQI score of 9.1 vs. 6.2 in those who did not suffer from ENL.[29] Lepra reactions are immunological mediated inflammation that may occur before, during or after the completion of multidrug therapy (MDT). Type 2 reactions or ENL is a serious debilitating immunological complication of lepromatous leprosy (LL) and borderline lepromatous (BL) leprosy. It may manifest as tender erythematous subcutaneous nodules with the presence of systemic illness. These reactions are accountable for most of the neuropathy and permanent disability.[30] This leads to decrease in daily activities and work & school as reported in our study. Absenteeism may lead to decreased work efficiency and financial loss as a result of low productivity, which in turn negatively impact the performance of the company and eventually leading to job insecurity.[31] Apart from that, patients with ENL often experience problems in body image, social isolation and also have feelings of stigma and embarrassment regarding their appearance. As a result of these problems, patients with leprosy are associated with QoL impairment and higher risk of psychiatric disorders such as depression and anxiety disorder. Majority suffered from moderate to severe depression and even had suicidal ideation after developing deformity.[32,33]

QoL measurement has been regarded as an important outcome in clinical management and patient care especially in patients with skin diseases.[34] Early recognition of skin diseases and appropriate treatment will reduce complications and physical disabilities or deformities, eventually minimize the impairment of QoL. Serial measurement of DLQI score would be able to detect small but meaningful changes over time; this may elucidate disease progression and determine therapeutic options.[34]

LIMITATIONS OF STUDY

The study was limited because of its cross-sectional design. It would beneficial to do a prospective study to assess the QoL upon the diagnosis, changes over the course of the treatment or after undergoing rehabilitation programme. We did not include leonine facies and pigmentation symptoms related to MDT as part of the criteria for facial deformity. Majority of the patients (85%) recruited from our Dermatology Outpatient Clinic were referred from primary care clinics for complications related to leprosy.

CONCLUSION

The QoL of the leprosy patients in Sabah was moderately impaired. There were significantly more patients with WHO grade 1 and 2 disability or facial deformity experiencing moderate to severe impairment in the QoL. The impairment in QoL was worse than other chronic skin diseases, such as acne, chronic urticaria, vitiligo, psoriasis and atopic dermatitis. Leprosy-related disabilities may predispose patients to develop psychosocial problems which may have negative impact on QoL. Thus, the management of leprosy patients should incorporate periodic assessment of quality of life in order to provide guidance to rehabilitation programme to achieve well-being.

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