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Health Related Quality of Life in Egyptian Leprosy Patients using DLQ and WHOQOL-BREF Questionnaires

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Abstract

Background: Leprosy is a chronic and complex infectious disease. It affects skin and the peripheral nerves causing nerve damage, pain, visible deformities and disabilities. Leprosy patients suffer from physical, psychological, social discrimination and stigmatization.

Objectives: To determine the health-related quality of life (HRQoL) in a group of leprosy patients in Egypt outlining their sociodemographic, dermatological and neurological characteristics.

Patients and methods: The study included 300 leprosy patients recruited from Benha Dermatology & Leprosy clinic and Abu Zaabal Leprosarium in Egypt. Patients were subjected to detailed history taking, dermatological and neurological examination (including DN4 questionnaire to assess pain), and assessment of HRQoL using Arabic version of DLQI and WHOQOL-BREF questionnaires.

Results: Patient's mean age was 59.4. 161 (53.67%) were males and 139 (46.33) were females. Lepromatous skin lesions were found in 150 (50.33%), while 137 (45.67%) had cutaneous drug side effects. Pure neurological leprosy was for 12 (4%) patients. Neuropathic pain was diagnosed in 195 (65%) of patients based on DN4 score (≥ 4). World Health Organization (WHO) grade 2 deformities were diagnosed in 62 patients (20.66%). The mean DLQI score was 11.58. Patients had the lowest mean scores in all domains of the WHOQOL-BREF which indicates a marked impairment of HRQoL.

Conclusions: Quality of life was impaired in 100% of leprosy patients. In Egypt leprosy causes significant impairment of patients' HRQoL even in fully treated patients. It is recommended to implement DN4 and WHOQOL-BREF questionnaires in research and routine assessment of leprosy patients.

Keywords: Leprosy; Neuropathic pain; Nerve damage; Quality of life

Introduction

Last decades have witnessed an increasing interest in psychological effects, the way in which a disease manifests itself in patients' daily lives or health related quality of life in patients suffering from various skin diseases. Skin diseases usually affect the person's sense of well-being, self-confidence, sexual attractiveness, work opportunities and social relationships. When there is a different outlook in a patient's skin, society act differently towards these patients. They are subjected to whispered comments, antagonism, insult or isolation [1]. The chronic nature of disease, long term treatment, lack of uniform effective therapy and unpredictable course are usually very demoralizing for patients suffering from skin diseases such as psoriasis, vitiligo, atopic dermatitis and chronic urticarial [2]. Leprosy has a slightly different story from other debilitating skin diseases. It is best seen as a chronic neurological condition rather than a simple skin disease. The clinical findings of leprosy are mainly the results of nerve damage caused by the disease [3]. Nerve damage is the hidden threat that leads insidiously and slowly to disability and deformity [4]. In addition to those adverse effects a skin disease has on patients' lives, leprosy due to its visible and crippling deformities, leads to social stigmatization and ostracization of the patients. It causes as well an extensive loss of manpower and economy loss to the society [5].

Clinical manifestations and severity of leprosy are dependent in large part upon the individual's immunologic response to the causative organism, *Mycobacterium leprae*. Leprosy is primarily a granulomatous disease of skin, peripheral nerves and mucosa of the upper respiratory tract. Individuals who have good cell mediated immunity are at the tuberculoid end of the Ridley-Jopling scale and have few skin lesions, however those who have low reactivity for *M. leprae* are at the lepromatous end of the scale, and have uncontrolled bacterial spread with multiple skin and mucosal lesions [6]. Peripheral nerve damage occurs across the spectrum. Nerve damage may occur before, during, or after treatment. Patients develop anaesthesia of the hands and feet, which puts them at risk of developing neuropathic injury. Weakness and paralysis of the small muscles of the hands, feet puts people at risk of developing deformity and contractures. Loss of the fingers and toes is caused by repeated injury in a weak, anaesthetic limb [3]. There is enlargement of affected nerve with or without tenderness, and standard regional patterns of sensory and motor loss [7]. The suffering of leprosy patients from chronic neuropathic pain is sometimes overlooked by clinicians who are more concerned with overt sensory loss and motor weakness during clinical assessment of patients; however the presence of pain is another disabling consequence of leprosy that adversely affects patients' lives. Neuropathic pain occurs as a consequence of

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disease affection of somatosensory system and could be present despite finishing MDT treatment and it does not respond to usual analgesics [3].

Commonly nerve damage progress insidiously in uncomplicated cases, however acute and subacute peripheral nerve changes may occur in complicated cases during lepra reactions [4]. In a subtype of leprosy, the pure or primary neural leprosy (PNL), there is clinical evidence of nerve damage, neural pain, numbness, paraesthesia, sensory and/or motor impairment and nerve thickening in absence of any history or clinical sign of cutaneous leprosy lesions [8]. Leprosy is still a public health problem. Worldwide, the number of cases of leprosy has decreased considerably as a consequence of appropriate detection and effective multidrug treatments. Nevertheless, new cases continue to occur in almost all endemic countries in Africa, South-East Asia, America, Eastern Mediterranean region including Egypt and Western Pacific region [9]. In the most recent report submitted to WHO from Egypt on the registered prevalence of leprosy, there were 651 new cases detected during 2016, of whom 51 cases suffer from grade 2 disabilities, plus 721 registered prevalent cases [10]. There are sparse data on the effect of leprosy on patients HRQoL in Egypt. The aim of the study was to explore how leprosy affects HRQoL in a group of Egyptian patients, outlining the socio-demographic, dermatological and neurological characteristics of patients.

Patients and Methods

Study design

This is a multi-centered cross-sectional observational study. The study was conducted in a period of one year and included 300 leprosy patients attending the dermatology outpatient clinic at Benha Dermatology & Leprosy clinic, Mansoura Dermatology & Leprosy clinic and Abu Zaabal Leprosarium, Egypt.

Inclusion criteria

Egyptian leprosy patients included in the study were older than 16 years old, mentally competent, diagnosed with the disease, have received at least two supervised doses of the specific therapy, and they are willing to participate.

Exclusion criteria

Those excluded were patients with other systemic diseases like: diabetes mellitus, congestive heart failure, coronary insufficiency, peptic ulcer, hepatic or renal insufficiency, patients with other cutaneous diseases hard to control such as atopic dermatitis, psoriasis, and vitiligo, patients with disabilities of some other known cause, and patients who verbally refuse to take part in the study.

Study procedures

All patients were subjected to detailed history taking and clinical examination to determine the dermatological and neurological manifestations of leprosy. A face-to-face interview was conducted by a dermatologist using the Arabic version of the Dermatology Life Quality Index (DLQI), Arabic version of WHOQOL-BREF and DN4 questionnaires.

Dermatological examination: Leprosy was diagnosed clinically based on detailed skin examination, including testing for loss of sensation in skin lesions, and confirmed by an experienced dermatologist. Classification was based on the WHO system of lesion counting guidelines (PB leprosy, ≤ 5 lesions; MB leprosy, >5 lesions) [11].

Neurological examination: It was done to determine nerve thickness and/or tenderness as well as nerve functions. This was assessed in every patient. Sensory loss was detected by the ballpoint pen test, and motor loss by voluntary muscle testing (VMT) [12,13]. These are reliable methods widely used in leprosy clinics.

Deformities and disabilities: Hands and feet were examined for presence/absence of any visible deformities, muscle atrophy, contractures, loss or partial resorption of fingers/toes, fissures, ulcers, callosities, scars. Eye examination was done to assess vision, presence/absence of lagophthalmos, iridocyclitis and corneal opacities. The WHO 1988 'disability' grading scale (0-2, for both eyes, hands and feet) was used as a measure of impairment (Table 1). The WHO grades for the individual impairment in these 6 sites were summed to form the 'sum-score', the so called Eyes, Hands, and Feet (EHF) score (minimum 0, maximum 12) [14].

The Douleur neuropathique 4 (DN4) questionnaire: The DN4 questionnaire is a 10-item diagnostic tool to assess clinical conditions associated with neurological lesions [15].

The Dermatology Life Quality Index (DLQI) questionnaire: Dermatology Life Quality Index (DLQI) is a skin disease-specific HRQoL assessment questionnaire designed by Finaly and Khan in 1994. It consists of 10 questions grouped into six domains: symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Each question has four response alternatives, corresponding to scores from 0 to 3. DLQI is calculated by summing the scores of all questions. The maximum score is 30 and the minimum score is 0. The higher the score, more quality of life was impaired [16].

The WHOQOL-BREF questionnaire: The WHOQOL-BREF contains a total of 26 questions. Two questions on the overall perception of quality of life and health status, and 24 questions each represent an individual facet of quality of life. They are grouped into 4 domains: physical, psychological, social relationships, and environmental. Each item uses a 5-point response scale. Scores are scaled in a positive direction with higher scores indicating a higher quality of life. The possible raw score ranges for each domain are as follows: Physical Health=28, Psychological=24, Social Relationships=12 and Environment=32 [17].

Statistical analysis: The collected data were summarized in terms of mean ± Standard Deviation (SD) and range for quantitative data and frequencies and percentages for qualitative data. Comparisons between the different study groups were carried out using the Chi-square test ($\chi 2$) and Fisher's Exact Test (FET) to compare proportions as appropriate. The Student t-test (t) was used to detect mean difference between two groups and the Analysis Of Variance (ANOVA) test (F) was used to compare more than two groups. Pearson correlation coefficient (r) was used to test for the correlation between the quality of life scores. A P-value <0.05 was considered statistically significant (S), a P-value <0.001 was considered statistically highly significant (HS), while a P-value >0.05 was considered statistically non-significant. The statistical analysis was conducted using STATA version 11 (STATA corporation, College Station, Texas).

Results

Socio-demographic features

Three hundred Egyptian leprosy patients were enrolled in the study. Most of them (97.67%) were living in villages surrounding Abu Zaabal, Benha and Mansoura cities were the study was done. Their age ranged between 18 and 70 years old with mean age 59.4 ± 29.8. 161 (53.67%)

were males and 139 (46.33) were females. Married patients were 226 (75.33%) and 74 (24.67%) were single. 202 (67.33%) were working while 98 (32.67%) were not working (Table 1).

Dermatological examination

Initial diagnosis and classification of leprosy according to patients' records at the time of first presentation was MB leprosy in 297 (99 %) and PB in 3 (1%) patients (Table 1). At time of the study, skin examination revealed lepromatous skin lesions in 150 (50.33%), and cutaneous side effects from MDT in 137 (45.67%) patients. 12 (4%) patients had never developed any skin lesions. These patients represent patients with pure neurological leprosy. Sites of lesions and presence or absence of sensations in the lesion are shown in Table 1.

Neurological examination

The ulnar nerve was the only thickened nerve in 64 (21.33%) patients, the common peroneal nerve in 21 (7%), and both nerves were thickened in 45 (15%) patients. No thickened nerves detected in 170 (56.67%) patients. Sensations were normal in the hands of 211 (70.33%) patients (Grade 0), 60 (20%) patients had sensory loss (Grade 1) and 29 (9.67%) patients had deformities (Grade 2). In the feet 237 (79%) patients had normal sensation (Grade 0), 25 (8.33%) patients had sensory loss (Grade 1) and 38 (12.67%) patients had deformities (Grade 2) (Table 2).

Hands and feet	
Grade 0	No loss of sensation, no visible deformity or damage (muscle power normal)
Grade 1	Loss of sensation is present, but no visible deformity or damage (muscle power normal)
Grade 2	Visible deformity or damage is present (loss of sensation and muscle power weak/paralysed)
Eyes	
Grade 0	No eye problem due to leprosy (normal vision, no lid lag, and blinking present)
Grade 1	Eye problem due to leprosy is present, but vision not severely affected (can count fingers at 6 m)
Grade 2	Severe visual impairment (cannot count fingers at 6m) also includes lagophthalmos, iridocyclitis and corneal opacities

Table 1: WHO disability grading [14].

Deformities and disabilities

World Health Organization (WHO) Grade 2 disabilities were diagnosed in 62 (20.66 %) patients. EHF score range was 0-6 with mean score 0.96 ± 1.63 SD (Tables 2 and 3)

Variable (No=300)		No.	%
Age (years)	<20	31	10.33
	20-39	113	37.66
	40-59	121	40.33
	>60	35	11.67
	Mean ± SD	59.4 ± 29.8	
	Median	30	
	Range	18-70	
Gender	Male	161	53.67
	Female	139	46.33
Marital status	Single	74	24.67
	Married	226	75.33
Residence	City	7	2.33
	Village	293	97.67
Employment/Occupation	Yes	98	32.67
	No	202	67.33
WHO leprosy Classification	Paucibacillary	3	1
	Multibacillary	297	99
Site of lesion	Upper limb	59	19.67
	Abdomen	7	2.33
	Lower limb	18	6
	More than one site	216	72
Sensation in the lesion	Present	169	56.33
	Absent	131	43.67
Thickened nerve	Ulnar nerve only	64	21.33
	Common peroneal nerve only	21	7
	Both nerves	45	15
	Absent	170	56.67
Neuropathic pain	Present (DN4 ≥ 4)	195	65
	Absent (DN4<4)	105	35
DN4 score	Mean ± SD	3.35 ± 2.22	
	Range	0-9	

Table 2: Socio-demographic, dermatological and neurological characteristics of patients.

Scores		1		2		3		4		5		6		7		8	
		R	P	r	P	r	P	r	P	r	P	r	P	r	P	r	P
DLQI		1															
WHOQOL-BREF	Physical domain	(-) 0.54	<0.001 (HS)	1													
	Psychological domain	(-) 0.52	<0.001 (HS)	0.71	<0.001 (HS)	1											
	Social domain	(-) 0.61	<0.001 (HS)	0.58	<0.001 (HS)	0.57	<0.001 (HS)	1									
	Environment domain	(-) 0.40	<0.001 (HS)	0.65	<0.001 (HS)	0.66	<0.001 (HS)	0.52	<0.001 (HS)	1							
	Overall quality and general health	(-) 0.48	<0.001 (HS)	0.6	<0.001 (HS)	0.54	<0.001 (HS)	0.56	<0.001 (HS)	0.48	<0.001 (HS)	1					
DN4		(-) 0.18	0.002 (S)	(-) 0.25	<0.001 (HS)	(-) 0.27	<0.001 (HS)	(-) 0.12	0.03 (S)	(-) 0.25	<0.001 (HS)	(-) 0.13	0.02 (S)	1			
WHO disability		-0.1	0.09	-0.26	<0.001 (HS)	-0.22	<0.001 (HS)	-0.09	0.11	-0.25	<0.001 (HS)	-0.17	0.004 (S)	0.72	<0.001 (HS)	1	

Table 3: Correlation between DLQI, WHOQOL-BREF domains, DN4, and WHO disability scores.

The DN4 questionnaire

Neuropathic pain was diagnosed in 105 (35%) of patients based on DN4 score (≥ 4). The DN4 score range was 0-9, and its mean score was 3.35 ± 2.22 SD. Pain was associated in 61.59% of patients with presence of skin lesions (Tables 1,4-6).

The DLQI questionnaire

The mean DLQI score was 11.58 ± 5.56. Extremely large effect on patients' quality life was found in 3.67% of patients , very large effect in 43.67% , moderate effect in 38.67%, and 14.0% of patients showed small effect (Tables 4-7).

Variable (No=300)			Age (years)										Test	P
			<20 (No s31)		20 (No.s 37)		34 (No.s 76)		40 (No.s 121)		>60 (No.s 35)			
			No.	%	No.	%	No.	%	No.	%	No.	%		
DLQI		Small effect (2-5)	0	0	0	0	0	0	36	29.8	6	17.1	FET	<0.001 (HS)
		Moderate effect (6-10)	12	38.7	19	43.24	26	34.2	53	43.8	9	25.7		
		Thy kale effect (11-20)	16	51.6	17	45.95	49	64.5	31	25.6	18	51.4		
		Extremely large effect (2430)	3	9.68	4	10.81	1	1.32	1	0.83	2	5.71		
WHOQOL	Physical domain	Mean ± SD; (range)	16.64 ± 1.62; (16-25)		19.11 ± 3.37; (17-27)†		19.29 ± 0.93; (17-26)†		21.02 ± 2.1; (15-27)†††!		19.6 ± 3.78; (15-27)†$		Fs=24.75	<0.001 (HS)
	Psychological domain	Mean ± SD; (range)	15.06 ± 1.86; (12-19)		16.16 ± 2.52; (12-22)		16.09 ± 2.04; (12-22)		18.31 ± 2.91; (13-24)†††!		16.48 ± 3.18; (10-23)$		Fs=15.47	<0.001 (HS)
	Social domain	Mean ± SD; (range)	7.45 ± 1.8; (4-12)		7.94 ± 1.78; (5-12)		7.51 ± 1.43; (5-11)		9.81 ± 2.04; (5-13)†††!		8.11 ± 1.78; (5-12)$		Fs=25.17	<0.001 (HS)
	Environment domain	Mean ± SD; (range)	17.29 ± 5.28; (8-29)		20.11 ± 5.5; (9-29)		20.34 ± 3.73; (14-30)†		23.36 ± 4.51; (9-31)†††!		20.11 ± 3.89; (13-30)$		Fs=14.69	<0.001 (HS)
	Overall quality and general health	Mean ± SD; (range)	2.22 ± 0.5; (2-4)		2.81 ± 0.81; (2-4)†		2.41 ± 0.54; (2-4)‡		3.48 ± 0.67; (2-4)†‡!		3.66 ± 0.59; (2-4)†‡!		Fs=55.15	<0.001 (HS)
DN4		Absent Nueropathic pain (<4)	15	48.4	23	62.16	49	64.5	85	70.3	23	65.7	χ^2=537	0.25
		Neuropathic pain (≥4)	16	51.6	14	37.84	27	35.5	36	29.8	12	34.3		
		Mean ± SD; (range)	4.16 ± 2.9; (0-8)		3.51 ± 2.3; (0-9)		3.54 ± 2.34; (0-9)		3.05 ± 1.8; (0-9)		3.22 ± 2.38; (0-8)		F=1.89	0.11

† Significant differences compared to <20 group;
‡ significant differences compared to 20-30 group;
! significant differences compared to 30-40 group;
$ significant differences compared to 40-60 group;
S: Significant P<0.05;
HS: highly significant P<0.001

Table 4: Correlation between age and DLQI, WHOQOL-BREF and DN4 questionnaires scores.

Variable (No -300)			Sex				Test	P
			Male (No-161)		Female (No-39)			
			No.	%	No.	%		
DLQI		Small effect (2-5)	42	26.09	0	0	χ^2=44.62	<0.001 (HS)
		Moderate effect (6-10)	58	36.02	58	41.73		
		Very large effect (11-20)	58	36.02	73	52.52		
		Extremely large effect (21-30)	3	1.86	8	5.76		
WHOQOL	Physical domain	Mean ± SD; (range)	20.45 ± 3.04; (15-27)		18.9 ± 1.79; (15-26)		t=5.27	<0.001 (HS)
	Psychological domain	Mean ± SD; (range)	17.7 ± 3.22; (10-24)		16.05 ± 2.02; (12-21)		t=5.22	<0.001 (HS)
	Social domain	Mean ± SD; (range)	9.12 ± 2.10; (5-13)		7.91 ± 1.88; (4-12)		t=5.23	<0.001 (HS)
	Environment domain	Mean ± SD; (range)	22.51 ± 4.89; (9-31)		19.66 ± 4.41; (8-30)		t=5.26	<0.001 (HS)
	Overall quality and general health	Mean ± SD; (range)	3.34 ± 0.9; (2-4)		2.61 ± 0.55; (2-4)		t=7.97	<0.001 (HS)
DN4		Absent neuropathic pain (<4)	117	72.67	78	56.12	χ^2=8.99	0.003 (S)
		Neuropathic pain (≥ 4)	44	27.33	61	43.88		
		Mean ± SD; (range)	3.14 ± 2.28; (0-9)		3.6 ± 2.13; (0-8)		t=1.82	0.07

Table 5: Correlation between gender and and DLQI, WHOQOL-BREF, and DN4 questionnaires scores.

Variable (No=300)			Neurological manifestations				Test	P
			Present (No=106)		Absent (No=194)			
			No	%	No.	%		
DLQI		Small effect (2-5)	0	0	42	21.65	FET	<0.001(HS)
		Moderate effect (6-10)	74	69.81	42	21.65		
		Very large effect (11-20)	30	28.3	101	52.06		
		Extremely large effect (21-30)	2	1.89	9	4.64		
WHOQOL	Physical domain	Mean ± SD; (range)	18.87 ± 2.32; (15-27)		20.2 ± 2.7; (15-27)		t= 4.28	<0.001 (HS)
	Psychological domain	Mean ± SD; (range)	15.8 ± 2 .51; (10-24)		17.56 ± 2.84; (10-24)		t=5.32	<0.001 (HS)
	Social domain	Mean ± SD; (range)	8. 2 ± 1. 83; (4-12)		8.75 ± 2.19; (5-13)		t=2.21	0.03 (HS)
	Environment domain	Mean ± SD; (range)	19.37 ± 5.07; (9-31)		22.18 ± 4.47; (8-30)		t=4.97	<0.001 (HS)
	Overall quality and general health	Mean ± SD; (range)	2.87 ± 0.76; (2-4)		3.1 ± 0.87; (2-4)		t=2.29	0.02 (S)
DN4		Absent neuropathic pain (<4)	1	0.94	194	100	χ^2=295.64	<0.001 (HS)
		Neuropathic pain (≥ 4)	105	99.06	0	0		
		Mean ± SD; (range)	5.89 ± 1.46; (3-9)		1.97 ± 1.02; (0-3)		t=27.18	<0.001 (HS)

Table 6: Correlation between neurological manifestations and and DLQI, WHOQOL-BREF and DN4 questionnaires scores.

Variables (NO=300)		No.	%
Peripheral sensory loss	Absent	211	70.33
	Present	89	29.67
VMT	Normal	262	87.33
	Weak	38	12.67
Hands	G0	211	70.33
	G1	60	20
	G2	29	9.67
Feet	G0	237	79
	G1	25	8.33
	G2	38	12.67
Eyes	G0	266	88.67
	G1	-	-
	G2	34	11.33
WHO disability grading	G0	194	64.67
	G1	44	14.67
	G2	62	20.66
EHF score Mean ± SD (Range)			0.96 ± 1.63 (0-6)

Table 7: Sensory and motor impairment, WHO disability grading and EHF score of patients.

DLQI (No=300)		No.	%
DLQI scores categorization	Small effect (2-5)	42	14
	Moderate score (6-10)	116	38.67
	Very large effect (11-20)	131	43.67
	Extremely large score (21-30)	11	3.67
Overall DLQI score	Mean ± SD; (Range)	11.58 ± 5.56 (2-28)	

Table 8: Scores of DLQI questionnaire in the studied group.

WHOQOL-BREF Domains (No=300)		Mean ± SD	Range
WHOQOL-BREF scores	Physical domain	19.73 ± 2.65	15-27
	Psychological domain	16.94 ± 2.85	10-24
	Social relationships domain	8.56 ± 2.09	4-13
	Environment domain	21.19 ± 4.88	8-31
	Overall quality and general health	3.02 ± 0.83	2-4

Table 9: Scores of WHOQOL-BREF questionnaire in the studied group.

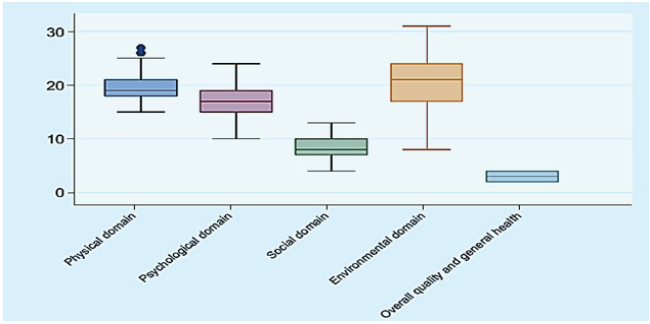

Figure 1: WHOQOL-BREF Domains.

The WHOQOL-BREF questionnaire

The WHOQOL-BREF mean score in overall quality of life and general health facets was 3.02 ± 0.83, 8.56 ± 2.09 in social relationships, 16.94 ± 2.85 psychological, 19.73 ± 2.65 in physical and 21.19 ± 4.88 in environment domains (Tables 4-6,8,9) (Figure 1).

Discussion

In Egypt, Leprosy was eliminated as a major public health problem in 1994 and the WHO target of decreasing the disease prevalence to less than one case per 10,000 populations was achieved on national level. However, there are focal points in some governorates where the rate is still high [18]. Thus leprosy is still a concern in Egypt as well as many countries. The current Global Leprosy Strategy, 2016-2020, accelerating towards a leprosy-free world, is innovative as it gives, in addition to a solid medical component, increased visibility and weight to the human and social aspects affecting leprosy control. Yet, there is a need for reliable tools and data to address these life quality aspects and build strategies and action planes to achieve these goals [19]. Measurement of HRQoL provides health policies makers with the required data about the burden a disease and/or disability has on physical, psychological and social wellbeing of individuals. It also reflects populations' differences in educational level, employment status, income, marital state that affects their life, and assesses effectiveness of health policies and interventions [20].

The DLQI is a dermatology specific HRQoL questionnaire. It is available in 55 languages and was used in 32 countries to assess the impact of different skin diseases and its treatment on patients' lives as

psoriasis, vitiligo, atopic dermatitis, viral warts, acne vulgaris and proved reliable and valid in multiple studies [21]. The current study is the first to determine DLQI of leprosy patients in Egypt, range of DLQI scores was 2-28 with mean score 11.58. This is higher than those reported in other dermatoses among Egyptian patients as atopic dermatitis in children and adults (9.8,11.0) respectively, melasma (5.8), and acne vulgaris (6.42), but less than DLQI score of vitiligo (12.3), psoriasis (14.6), and leishmaniasis (12.67) [22-27]. In contrast to our study, a study done in China reported mean DLQI score in lepromatous leprosy patients (18.78), being higher than in control (healthy volunteers or patients with other dermatoses) [28]. The DLQI is a simple practical questionnaire that is recommended for routine clinical use, however, there are various issues that doubt its use in observational and interventional research and in important medical decision-making processes, regarding its uni-dimensionality, and differential item functioning [29]. We postulated that The WHOQOL-BREF may overcome DLQI limitations by its broader questions, multiple domains, and being cross-culturally valid HRQoL assessment tool.

The WHOQOL-BREF is a 26-item version of the WHOQOL-100. It has good to excellent psychometric properties of reliability, as reflected by its four domains: physical, psychological, social and environmental. It is available in 19 different languages [30]. Its Arabic version has an impressive reliability and validity index that ensures its representation of the same constructs across cultures [31]. In the present study, The WHOQOL-BREF mean score in overall quality of life and general health facets was 3.02 ± 0.83. Patients had low mean scores in all domains. The most affected domains were the social, psychological and physical domains more than the environmental domain. It appears that people affected by leprosy are not satisfied with their social life. Leprosy affects specific items of social domain in The WHOQOL-BREF, such as personal life, sexual relationships and social support from family and friends. Low scores in physical and psychological domains may be because neurological pain affects specific items of these domains. Presence of pain was associated with anxiety, depression, poor quality of sleep and a reduced capacity to perform daily and occupational activities, and it also impairs participation in social activities.

Finding better score in environmental domain is in agreement with results of a similar study in Bangladesh. Their study showed better scores for "satisfaction with accessibility to health services" and "satisfaction with transport" as well [32]. This is on the contrary to results of another study in India, patients scored low in physical, psychological, and environmental domains but not in social domain. This may be attributed to effective programs adopted there for leprosy patients' rehabilitation [33]. The HRQoL scores found in this study are consistent with the literature [34-37]. Also there was no difference in the overall HRQoL scores between the DLQI and the WHOQOL-BREF questionnaires. The use of 2 instruments for HRQoL measurement in the study provides strength to its results and the good agreement between them probably results more from the actual presence of adverse effects of leprosy on patients' lives than from similarity of both instruments, because their structure is quite different. Age, sex, and occupation were the sociodemographic factors associated with more impact of leprosy on HRQoL in the studied leprosy patients. Young age had a highly significant impact on HRQoL than old age, which means that leprosy in elderly patients does not cause them as much problems with their family life, social relationships, and self-respect unlike young ones.

The impact on female patients was significantly more than males. Women are more embarrassed by and self-conscious about the disease. However in another study, males were associated with worse HRQoL [38]. Interference with work of the patient causes economic losses and psychological trauma, especially when it involves the family provider, who may end up unemployed and without social insurance. Statistically significant variation was observed with occupational status. Work is an important factor in achieving a high level of subjective wellbeing and life satisfaction. No significant differences in HRQoL scores related to type of leprosy and site of the lesion were found in this work. Impact on HRQoL in patients with chronic pain (DN4 score ≥ 4) was significantly more adverse. Visible deformities and disabilities contributed also to low HRQoL. It affected their mobility, interpersonal relationships, marriage, employment, leisure and social activities. These results are comparable to previous studies [39,40].

Conclusion

There was no difference in the overall HRQoL scores between the DLQI and the WHOQOL-BREF questionnaires. The DLQI is easily administered and do not impose a great burden on the respondent, however the WHOQOL-BREF questionnaire provide detailed multidimensional assessment data that are essential for researchers and could be useful in epidemiological studies and for health policy providers. The DN4 is a useful neurological assessment tool and could be used in large epidemiological surveys and clinical settings.

Conflict of Interest

The authors declare that they have no conflict of interest.

Ethical Approval and Informed consent

The methods used in the study were in accordance with the ethical standards of and approved by the Research Ethics Committee-Benha Faculty of Medicine (REC-bfomed). All participants were fully aware of the purpose of the study and gave verbal consent for being included in the study.

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