

# IJMA



## INTERNATIONAL JOURNAL OF MEDICAL ARTS

VOLUME 6, ISSUE 8, AUGUST 2024



**P- ISSN: 2636-4174**  
**E- ISSN: 2682-3780**





Available online at Journal Website  
<https://ijma.journals.ekb.eg/>  
 Main Subject [Dermatology]



## Original Article

# The Impact of Leprosy on Quality of Life of Patients and Their Families

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## ABSTRACT

### Article information

Received: 20-08-2023

Accepted: 19-04-2024

DOI: [10.21608/ijma.2024.230412.1783](https://doi.org/10.21608/ijma.2024.230412.1783).

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**Citation:** Abd Elmonem HF, Atallah RB, Fouda I. The Impact of Leprosy on Quality of Life of Patients and Their Families. IJMA 2024; August; 6 [8]: 4749-4754, doi: 10.21608/ijma.2024.230412.1783.

**Background:** Hansen's disease [HD], often known as leprosy, is a bacterial disease with a long history that is still prevalent today. This infection can manifest in a number of different ways, causing damage to peripheral nerves, skin, and testes. The functional activity limitations [FALs] caused by leprosy are well understood. Physical and mental well-being, autonomy, social connections, perspectives, and the natural setting all contribute to one's quality of life [QoL].

**Aim of the work:** This work aimed to measure how leprosy affects patients' and their family's quality of Life.

**Patients and Methods:** This cross-sectional study involved 100 patients and their families. All of them were recruited from Dermatology, Venereology & Andrology Department Outpatient Clinics, Al-Azhar University Hospitals [Damietta], and Dermatology and Leprosy Hospitals in Tanta and Damietta. The quality of life of leprosy patients was evaluated using the Dermatology Life Quality Index [DLQI].

**Results:** There was a significant relationship among [DLQI] result of patients and different lesion sites except for mucous lesions. Regarding family questionnaire, the majority of participants [87%] reported being sympathetic, and the minority of patients feel afraid with [4%], and [9%] feel normal when seeing a leprosy patient.

**Conclusion:** Leprosy severely affects the patient's and his/her family quality of life. The disability is the major important factor for the degree of quality of life impairment. There is still a need to raise awareness about lepromatous leprosy and its effects on patients' quality of life and the general public's understanding of the disease

**Keywords:** Quality of Life; Leprosy; Disability; Dermatological; Deformities



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## INTRODUCTION

Leprosy is an old bacterial illness can be treated but remains a serious issue in many parts of the world. *Mycobacterium leprae* bacillus infection causes Hansen's disease [HD] <sup>[1]</sup>. Bacterial infection of the skin causes dermatological symptoms, while infection of the nervous system causes axonal malfunction and demyelination, leading to sensory loss and the disabilities and deformities <sup>[2]</sup>. Nasal droplet infection is likely the primary mode of transmission. It has also been shown that direct dermal implantation, such as that used in tattooing, and contact with infected soil can both lead to transmission <sup>[3]</sup>.

Leprosy is a mycobacterial infection that causes many symptoms because the invading bacillus attacks the peripheral nerve system. When nerves are affected, there is swelling, discomfort, and a loss of sensory and motor function. Numbness, hypohidrosis, and a loss of temperature sensation are the results of damage to the tiny cutaneous nerve fibers <sup>[4]</sup>.

As a result of leprosy-related disabilities, an estimated 3 million people around the world face severe social stigma and isolation, difficulties in interpersonal relationships and mental health, and a compromised capacity for productive work <sup>[5]</sup>.

The functional activity limitations [FALs] that people with leprosy face are well-documented. Leprosy responses, nerve involvement, multibacillary leprosy, and a delay in diagnosis and/or treatment are the primary risk factors for FALs. However, how exactly these FALs affect people's QoL is still mostly unknown. QoL encompasses the multifaceted nature and subjective experience of QoL as a whole, but it is most commonly used to refer to the effect of a disease or injury on QoL <sup>[6]</sup>. Isolation and confinement are also experienced by the patient's family <sup>[7]</sup>.

## PATIENTS AND METHODS

This cross-sectional study was conducted on 100 leprosy patients and 100 families of the same patients who came for following up in Outpatients Clinics of Dermatology, Venereology and Andrology department of Al-Azhar University Hospital [Damietta] and Dermatology & Leprosy Hospitals in Tanta and Damietta.

**Inclusion criteria:** Any patient suffering from leprosy and their families

**Exclusion criteria:** Diabetes mellitus, excessive alcohol intake, immunocompromised, and patients whose mental or physical health interfered with the assessment of the patients or their families were excluded from the study.

In order to characterize the demographics and health of patients, a semi-structured questionnaire was developed.

**Every patient was subjected to the following:** History taking [Personal history, Present history, previous treatment, Current treatment, associated diseases and Family history of leprosy], Examination of skin, nerves and mucous membranes and the quality of life of leprosy patients was evaluated using the [DLQI]. Each patient's questionnaire was administered by the same researcher and his or her family.

### Families answered a questionnaire

**Ethical consideration:** A written informed consent was taken from all patients and their families. In addition, the study was approved by an Ethics Committee of Damietta Faculty of Medicine IRB [00012367], Al-Azhar University, Egypt

### Study procedures

The impact of leprosy on patients' quality of life and on their families was explored through two separate surveys. In order to collect information about the demographics and health of those with leprosy, a semi-structured questionnaire was developed. Gender, age, level of education, and profession were all included in the demographic profiles. Disease profiles contained information on both prognosis and severity of impairment. **Dias et al.** <sup>[8]</sup> state that the initial questionnaire was given to all patients showing cardinal indications of leprosy and giving written informed consent to take part in the study. For this study, we evaluated the quality of life of leprosy patients using [DLQI]. The same researcher administered the questionnaire to all of the patients. There are only ten items on this approved questionnaire. Each answer is worth three points. The DLQI ranges from 0 to 30, with 30 being the highest and 0 the lowest possible. If the score is high, QoL is severely compromised. A case record form was used to document the patient's history and the results of the clinical examination. After patients were given a thorough explanation of the DLQI questionnaire in their choice language, they were asked to complete the questionnaire. We computed, compared, and analyzed DLQI scores. The initial visit was used to collect all of the clinical information.

**Nisar et al.** <sup>[9]</sup> created a second questionnaire that was used to assess the participants' QoL as family members of leprotic patients. Age, sex, education level, employment, and household income were among the socio-demographic questions asked.

The diagnostic process for leprosy patients might have involved a combination of methods. The primary method for diagnosing leprosy is through clinical symptoms. This includes the presence of skin lesions, numbness, loss of sensation, and nerve damage, which are characteristic signs of the disease. Suspected diagnoses could have been made based on these symptoms and patients' medical history, guiding further evaluation. For confirmation, various diagnostic tests might have been employed. This could include skin biopsies, in some cases, a skin biopsy may be performed to confirm the diagnosis. A small sample of skin tissue is taken from the affected area and

examined under a microscope to detect the presence of the bacteria that cause leprosy. Laboratory tests such as slit-skin smear microscopy or PCR might have been utilized to detect the bacteria or its DNA in skin samples. Culture of the bacteria in specialized laboratory settings could have been another method, though it's less common due to the slow growth of the bacteria.

The DLQI ranges from 0 to 30, with 30 being the highest and 0 the lowest possible. If the score is high, QOL is severely compromised. A case record form was used to document the patient's history and the results of the clinical examination. After patients were given a thorough explanation of the DLQI questionnaire in their choice language, they were asked to complete the questionnaire. We computed, compared, and analyzed DLQI scores. The initial visit was used to collect all of the clinical information. If the DLQI scores fall within the range of 0-1, it indicates that leprosy has no significant effect on quality of life. Scores between 2 and 5 suggest a small effect, 6-10 indicate a moderate effect, 11 and 20 imply a large effect, and scores between 21 and 30 indicate a very large to extremely large effect.

**Data management and Statistical Analysis:** IBM's Statistical Package for the Social Sciences, Version 24 [May 2016], was used for data entry, processing, and statistical analysis. Qualitative data were expressed as percentages as well as frequencies, whereas quantitative data were expressed as mean as well as standard deviation. Pearson correlation was used to measure linear correlation between data. Statistical significance was defined as a p-value below 5%.

## RESULTS

In this study 55% of cases were females and 45% were males. Mean age was 57.04 years with SD of 13.54. Only 8 [8%] cases were educated. Disease duration mean was 21.78 years with SD of 12.73 [Table 1]. In addition, 43 patients [43%] had Skin Patches, 7 patients [7%] had Nodules, 7 patients [7%] had Thick, Dry skin, 51 patients [51%] had Painless Ulcer, 3 patients [3%] had Painless Swelling, and 54 patients [54%] had

Loss of eyebrow. 29 patients [29%] had Numbness, 7 patients [7%] had Muscle weakness, 2 patients [2%] had Enlarged nerve and 61 patients [61%] had Eye problem. 1 patient [1%] had Stuffy Nose, 33 patients [33%] had Nose Bleeding and 33 patients [33%] had Nose Bleeding. 55 patients [55%] had Shortening of Toes [Table 2].

Regarding DLQI, mean result was 12.93 with SD of 6.3. Also, 9 [9%] cases reported no Effect, 5 [5%] cases reported small effect, 16 [16%] cases reported moderate effect 2, [2%] cases reported large effect, 62 [62%] cases reported Very large effect and 6 [6%] cases reported extremely large [Table 3]. There was significant correlation between DLQI result of patients and different lesion sites except for mucous lesions. [Table 4].

Regarding family questionnaires, 87% of participants reported being sympathetic, 4% of patients feel afraid, and 9% of patients feel normal when seeing a leprosy patient. Regarding having a leprosy family member, 9% of patients feel afraid and 91% of patients were sympathetic. Only 19% of patients were ashamed to tell others if they had any lepers in their family. Regarding shaking hands with leprosy patients, 83% reported that they had no objection, and 17% refused to shake hands. Regarding sharing food from the same plate with an ex-leprosy patient, 83% reported that they had no objection, while 17% refused to share food. When we asked, "Do you think that it is difficult for leprosy patients to get married?" 40% reported yes, and the rest, 60%, reported no. When we asked, "Will you give a job to an ex-leprosy patient?" 82% reported yes, and 18% reported no. When we asked, "Do you feel that leprosy patients face an easy future?" 88% reported yes, and 12% reported no. When we asked, "Will you mind sitting side by side with lepers in a public conveyance?" 83% reported yes, and 17% reported no. When we asked, "Do you think that lepers should be treated with more compassion?" all [100%] reported yes. When we asked, "Will you panic when a leper approaches you?" 85% reported no, and 15% reported yes. When we asked, "Can you imagine yourself working with lepers?" 83% reported yes and 17% reported no [Table 5].

**Table [1]:** Demographic data of included subjects.

	Parameters	Value [n = 100]
Sex [n,%]	Female	55 [55%]
	Male	45 [45%]
Age [years]	Mean±SD	57.04 ± 13.54
	Min. – Max.	22 – 99
Education [n, %]		8 [8%]
Occupation [n,%]	Housewife	34 [34%]
	No occupation	54 [54%]
	Carpenter	2 [2%]
	Farmer	6 [6%]
	Teacher	1 [1%]
	Employee	1 [1%]
	Accountant	2 [2%]
Disease duration [Years]	Mean±SD	21.78 ± 12.73
	Range	1.5 - 59

Table [2]: Clinical Examination and Lesion site of included subjects.

	Parameters	Number [Percentage]
		[n = 100]
Skin [n,%]	Patches	43 [43%]
	Nodules	7 [7%]
	Thick, Dry skin	7 [7%]
	Painless Ulcer	51 [51%]
	Painless Swelling	3 [3%]
	Loss of eyebrow	54 [54%]
Nerve [n,%]	Numbness	29 [29%]
	Muscle weakness	7 [7%]
	Enlarged nerve	2 [2%]
	Eye problem	61 [61%]
Mucous Membranes [n, %]	Stuffy Nose	1 [1%]
	Nose Bleeding	33 [33%]
Others	Shortening Of Toes	55 [55%]

Table [3]: Results of DLQI [Patient Questionnaire] of the study group

Parameters		Values [n=100]
<b>DLQI</b>		
Mean±SD		12.93 ± 6.3
Min. – Max		0 – 26
Categories	NO Effect	9 [9%]
	Small effect	5 [5%]
	Moderate effect	16 [16%]
	large effect	2 [2%]
	Very large effect	62 [62%]
	Extremely large	6 [6%]

Table [4]: Correlation between different lesion sites and DLQI result of patients.

	DLQI	
	r	P. Value
Skin lesions	0.371	<0.0001
Nerve lesions	0.394	<0.001
Mucous lesions	0.049	0.62
Shortening Of Toes	0.474	<0.0001
Skin and Nerve lesions	0.470	<0.0001
Nerve and Mucous lesions	0.340	0.0005
Skin and Mucous lesions	0.351	0.0003
All lesions	0.520	<0.0001

**Table [5]: Distribution of Variables Regarding FQ Respondents Attitude for Leprosy.**

Variables	Frequency [n = 100]
How do you feel when you see a leprosy patient	
Normal	9 [9%]
Afraid	4 [4%]
Sympathetic	87 [87%]
How do you feel when you have a leprosy family member	
Afraid	9 [9%]
Sympathetic	91 [91%]
Feel ashamed to tell other if having any leper in family	19 [19%]
Will you shake hand with leprosy patient	83 [83%]
Will you share food from the same plate with an ex. leprosy patient	83 [83%]
Will you think that it Is difficult for leprosy patient to get Married	40 [40%]
Will you give job to ex. leprosy patient	82 [82%]
Do you feel that leprosy patient's face a bleak future	88 [88%]
Will you mind sitting side by side with leper in a public conveyance	83 [83%]
Do you think that leper should be late with more compassion	100 [100%]
Will you panic when leper approaches you	15 [15%]
Can you imagine your self-working with leper	83 [83%]

## DISCUSSION

Leprosy is a persistent skin, nerve, and mucous membrane infection caused by the bacteria *Mycobacterium leprae* [10]. Contact with patients who have a high bacillary index is the most common route of transmission [11].

In the current study, 55% of cases were females, the mean age was 57.04 years. Only 8 cases were educated. Disease duration mean was 21.78 years. In agreement with these results, **An JG et al.** [12] conducted a study aimed to describe the use of Dermatology Life Quality Index [DLQI] among patients with lepromatous leprosy. They found that in lepromatous leprosy group, there were 44 female and 20 males, the mean age was 45.6 and the mean disease duration was 8 years. However, they reported higher percentage of educated patients than the current work.

The same authors also reported comparable results to the current work regarding the type of the lesion. They revealed that there were twenty-eight patients with lepromatous leprosy with visible disabilities, including corneal opacities [9/28], iridocyclitis [13/28], lagophthalmos [4/28], malformation of hands/feet [20/28] and 36 patients with no disability were found.

In the present study, we found that there was significant correlation between DLQI result of patients and different lesion

sites except for mucous lesions. These results agree with **Lustosa et al.** [13] who aimed to analyze the health-related quality of life [HRQoL] of people in treatment for leprosy. They showed that regarding HRQoL, the SF-36 showed high scores that are consistent with a low compromise of HRQoL by leprosy. However, further statistical analysis revealed that there were some important determinants of the worsening of HRQoL in some patients.

In our results, regarding family questionnaires, 87% of participants reported being sympathetic, 4% of patients feel afraid, and 9% of patients feel normal when seeing a leprosy patient. These results are in line with **Barakat et al.** [14] who aimed to assess psychological problems and quality of life among leprosy patients and investigate the relationship between psychological problems and quality of life among leprosy patients. They found that most of the sample [84.0%] cohabitation with the family. The majority of the sample [72.0%] have family support. In addition, the majority of the sample [90.0%] have no family history of the disease.

Regarding respondent's attitude, the results of the current work are consistent with **Mankar MJ et al.** [15] who aimed to assess the knowledge, attitude and belief about leprosy in leprosy patients compared with community members and to find the perceived stigma among leprosy patients. Also aimed to evaluate the quality of life in leprosy patients as compared to community members using WHO Quality of Life assessment

questionnaire [WHOQOL- BREF]. They reported that regarding attitude toward leprosy, their study showed that among the control group, 43.10% of population said that they would not like food to be served by leprosy patients, compared to 13.73% in the study group. This was found to be statistically significant. As many as 67.24% in the control group said that either leprosy patients should be treated separately or isolated, which was also found to be statistically significant. 60.34% of people in the control group were against the idea of a key post to be given to leprosy patients, against 23.53% in the study group, which was found to be statistically significant. Almost 82.35% in the study group and 67.24% in the control group agreed that the patients should be given light work.

**Conclusion:** Overall, the results showed that disability is the most important factor in determining how severely lepromatous leprosy affects QOL. Therefore, it is still important to spread awareness about the impact of lepromatous leprosy on patients' [QOL], as well as other facts about the disease, such as the fact that it can be cured, is not spread through sexual contact, and that those who are infectious are no longer a threat to close contacts after 72 hours of receiving multidrug therapy.

**Point of strength:** This study was conducted on enough sample size. Strict inclusion and exclusion criteria and proper statistical analysis. This study was well designed and reliable

**Limitation of the study:** The study was conducted in single center, need longer period for follow up and absence of control group.

**Financial and non-financial disclosure:** None.

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# IJMA



## INTERNATIONAL JOURNAL OF MEDICAL ARTS

VOLUME 6, ISSUE 8, AUGUST 2024



**P- ISSN: 2636-4174**  
**E- ISSN: 2682-3780**