



International Journal of Infectious Diseases and
Preventive Medicine

Journal homepage: www.sciforce.org

Leprosy Scenario, pattern of disability, perceived stigma and impact on quality of life in post-elimination era: a seven year study from North India

Shagufta Rather§, FaizanYounus Shah,* Akhtar S,* Hassan I,** Reeta Devi.** Bhat YJ§

Postgraduate institute, Department of Dermatology, Government Medical College, University of Kashmir, Srinagar, Jammu and Kashmir, India, 19000.

ARTICLE INFO

Article history:

Received: 20210710

Received in revised form: 20210810

Accepted: 20210818

Available online: 20220118

Keywords:

Leprosy;

Post-elimination era;

Disability;

Stigma;

quality of life;

WHOQOL-BREF

ABSTRACT

Background: Leprosy is an infectious disease associated with fear, aversion and social stigma, mostly due to crippling deformities. As prevalence of leprosy decreases, so does the experience with disease, especially for younger physicians. Leprosy can have a significant impact on the quality of life (QOL) of the affected person owing to the chronic nature, disabilities and deformities associated with the disease. A high degree of social stigma in a conservative place like Kashmir further complicates the problem. This has necessitated the need to revisit realms of disabilities in leprosy in our region. **Objective:** To study profile of leprosy patients, categorize the pattern of disabilities and assess its impact on the QOL of persons affected with leprosy in our region. **Materials and Methods:** A cross sectional study was conducted in a tertiary care hospital, over a period of 7 years. All patients diagnosed with leprosy were included in the project following an Institutional ethical committee clearance. Detailed history followed by a meticulous examination was done in all patients with distinctive attention to recording of disabilities. Grading of disabilities was done using the world health organization (WHO) grading of 1988. The assessment of QOL was done using WHOQOL-BREF scale. **Results:** Out of the 90 cases, 42 patients (46.67%) were found to suffer from a total of 72 disabilities with majority suffering from more than one, averaging 1.7 disabilities per person. 48 patients (53.33%) did not have any disability. Fourteen cases (15.56%) had grade 1 disability while grade 2 and grade 3 disability were seen in 23 (25.56%) and 5 (5.55%) cases respectively. The assessment of QOL using WHOQOL-BREF scale demonstrated the quality of life to be worst for the physical domain (median 42) followed by environmental (median 48), global (median 49), psychological (median 56) and social relations domain (median 57). **Conclusion:** Disabilities and deformities are commonly encountered in our leprosy patients and can have a significant physiological, psychological, economic and social impact on the patient. The various clinical characteristics of disease such as deformity, disability, reaction, have a significant impact on the QOL of patients contrary to previous beliefs.

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*Corresponding Author. Mobile Number +91 7889501893, Email id: shagufta.giri@gmail.com

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* (*M. leprae*), which affects primarily the peripheral nervous system, skin, mucous membranes and occasionally other tissues. Sensory nerve damage resulting in loss of sensations of pain, temperature and touch, and motor nerve damage leading to paralytic deformities are the major contributors to the development of deformities in leprosy.^{1,2}

Leprosy is a crippling disease associated with fear, aversion, prejudice and social stigma, mostly due to the crippling deformities and disabilities associated with the disease. Disabilities may occur as a result of reactions as well as direct consequence of disease progression. Delay in the diagnosis and treatment contributes further to their progression. Deformities can be primary due to direct involvement of tissues and peripheral nerves with *M.leprae*, causing sensory loss or motor paralysis. Secondary deformities occur as a result of damage to

the anaesthetic parts of the body by friction and trauma. The frequency and severity of disabilities in newly diagnosed cases of leprosy is an efficient marker, not just of disease transmission but also of the adeptness of healthcare machinery in early diagnosis and case detection.

Disabilities in leprosy can affect hands, feet, eyes and face.³ Deformities of hands include ulcers, cracks, scars, blisters, claw hand, wrist drop, dactylitis, contractures and resorption of fingers and stiff joints, etc. Deformities of feet include ulcers, cracks, scars, blisters, foot drop, claw toes, resorption of toes, contractures of tendoachilles and equinovarus deformity among others. Facial deformities include nasal defects, alar deformities, facial palsy, sagging of ear lobules, rat-bitten helix, to name a few. Ocular deformities like madarosis, depressed nasal bridge, corneal abrasions, cataracts, entropion, ectropion, lagophthalmos, and loss of vision may complicate the disease.

The onset and progression of disabilities in a leprosy patient is affected by various factors like age, sex, occupation, marital status, educational status, duration of disease, type of disease, reactional states, attitude towards disease, treatment status and availability of medical care.⁴

The disease received due attention when the government of India started the national leprosy control programme in 1955 and subsequently the national leprosy eradication programme (NLEP) in 1983 with a vision of 'leprosy-free India'. The goal of elimination at national level, with a prevalence of less than 1 per 10000 population, was achieved in December 2005.⁵ With the elimination of leprosy, a number of leprosaria were closed, and the vertical program of NLEP was converted to horizontal one, there by the dedicated healthcare staff were redistributed. The younger generation medical and paramedical staff failed to become familiar with the myriad of clinical manifestations of leprosy and its complications. More and more patients are being treated by physicians who have little experience with the diverse presentations of the disease, often resulting in delayed diagnosis. This results in the dual problem of continuity of leprosy bacilli transmission and a higher incidence of disabilities and deformities at diagnosis.

Quality of life (QOL) describes the perception of an individual regarding their life, encompassing various aspects like physical and psychological health, social relationships, and personal beliefs among others. The psychological health of people affected with leprosy is adversely affected due to the disease and depends on duration of disease, type of leprosy, deformity, nerve involvement and further complicated by economic and social factors. All these factors ultimately affect the QOL.⁶

Kashmir has a population of 69,07,623 as per census 2011. J&K is regarded as a low endemic region for leprosy; the prevalence in Kashmir being lower of the two, with a prevalence

rate (PR/10000) of 0.02 and annual new case detection rate (ANCDR/100000) of 0.19.⁷ However, these values don't present a holistic view of the situation as patients who continue to live with stigmata and deformities of leprosy are not accounted for in these figures. Any patient who has completed 12 months of multi-drug therapy (MDT) can be conveniently excluded from the figures even if he continues to suffer from reactions, disabilities and deformities caused by this dreaded disease. The number of patients who have completed treatment with MDT but continue to visit the dermatology department of our hospital for ongoing reactions and problems related to their deformities and disabilities is quite significant considering the exceptionally low values for PR and ANCDR.

In addition to these problems, a high degree of social stigma associated with the disease is still persisting in Kashmir which has a muslim dominated population and a highly conservative culture, acting as an obstacle to self-reporting and coercing the patient to hide the disease. This has necessitated the need to revisit the realms of deformities and disabilities in leprosy, so that early identification is ensured and early MDT is instituted to minimize handicap. The influence of leprosy on QOL also needs to be assessed for a better understanding of the impact this disease has on the life of the patient.

Aims and objectives: This study was conducted with an intention to study the profile of leprosy patients as well as to categorize the pattern of disabilities in these patients and identify the factors predisposing to their development in the low prevalence region of Kashmir. We also aimed to study the impact of the disease on QOL in leprosy patients.

Materials and Methods

It was across sectional study conducted in a tertiary care hospital of Kashmir over a period of 7 years. All the data of leprosy patients enrolled with our department, from January 2012 to December 2018, was compiled and subjected to statistical analysis. Institutional ethical committee clearance was sought before undertaking the study.

Inclusion criteria:

- 1) All patients who presented to our OPD and were diagnosed as having leprosy were included in the study
- 2) Patients who were diagnosed for the first time, patients already diagnosed and on treatment, defaulters as well as patients released from treatment and on surveillance, were all included.

Exclusion criteria:

- 1) Patients with disabilities/deformities resulting from causes unrelated to leprosy were excluded.

An informed consent was taken from all participants. A detailed history and meticulous examination was carried out in each patient. Demographic data like age, sex, occupation, marital status and educational status was recorded followed by a detailed history of the onset of disease, duration of disease, time lag in seeking treatment, symptoms suggestive of a reactional state, treatment history and availability of medicines and medical care. A detailed personal, past and family history was also taken. It was followed by a thorough general physical, systemic, cutaneous, nervous, musculoskeletal and ocular examination of the patients. The classification of leprosy was done using Ridley Jopling scale, modified to include pure neuritic leprosy, based majorly on clinical and histopathological criteria. In case of disparity between the two, histopathology took preference during allocation of patient to a group. Categorization into paucibacillary (PB) or multibacillary (MB) groups was done strictly as per the results of slit-skin smear (SSS). Consequently, cases with negative SSS were considered as PB while those with positive SSS were categorized as MB, regardless of number of skin lesions. Distinctive attention was given to the recording of disabilities and their causes. Grading of disabilities was done using the world health organization (WHO) grading of 1988 meant for statistical purposes.

In case of patients suffering from multiple disabilities, the highest grade of disability suffered by the patient was taken as the disability grading, e.g. if a patient had grade 1 disability of hands and grade 2 for feet, disability grading was assigned as grade 2. Cases afflicted with isolated deformities of the face like madarosis, leonine facies, etc did not form a part of the total disability count as these disabilities do not find place in the WHO grading of disabilities.

The effect of leprosy on the QOL was assessed using WHOQOL-BREF scale.⁸ It consists of 26 questions; two are general and the remaining 24 are divided into 4 domains – physical, psychological, social relationships and environmental. Each question is scored using 5-point response scale (1 = not at all, 2 = a little, 3 = moderately, 4 =mostly, and 5 = completely). The raw score of each dimension is 7–35, 6–30, 3–15, and 8–40,

respectively, with higher scores indicating a better QOL. Measures were taken to maintain the privacy and avoid any emotional embarrasment to the patients.

The records of patients with all investigations were maintained in separate files for each patient for easy reference and better management. The patients were managed collectively by a dermatologist, physician, orthopaedician and ophthalmologist depending upon the extent of disease and specific disabilities in individual patients.

Results:

The study included a total of 90 patients. The mean age of the patients was 34.46 ± 15.64 with an age range of 8 years to 70 years. The demographic data of the patients is presented in **Table 1**.The median duration of disease at the time of presentation was 12 months, extending from a minimum of one month to a maximum of 24 months. Relevant clinical characteristics are tabulated in **Table 2**. Slit skin smear test was done in all patients and was found to be positive in 88.89% of cases (n = 80/90). Accordingly, 88.89% of patients were classified as MB and 11.11% as PB. Bacterial index and morphological index of the tested samples is presented in **Table 3**. Out of the 90 cases, 42 patients (46.67%) were found to suffer from a total of 72 disabilities with majority suffering from more than one disabilities and deformities, averaging 1.7 disabilities per person. A detailed classification and grading of disabilities is presented in **Table 4 and Table 5**.

Highlight the commonly encountered disabilities. Hands were involved in 27 cases (30%), feet in 23 cases (25.56%), while involvement of face/ eyes was seen in 22 cases (24.44%). According to WHO disability grading of 1988 meant for statistical purposes, 14 cases (15.56%) had grade 1 disability while grade 2 and grade 3 disability was seen in 23 (25.56%) and 5 (5.55%) cases respectively. Thus, the grade 2 deformity rate per million comes out to 1.83.

Table 1: Demographic data of patients			
	Groups	Frequency	Percentage

Age	≤10 years	3	3.33% (n = 3/90)
	11-20 years	13	14.45% (n = 13/90)
	21-30 years	28	31.11% (n = 28/90)
	31-40 years	21	23.33% (n = 21/90)
	41-50 years	11	12.22% (n = 11/90)
	51-60 years	7	7.78% (n = 7/90)
	61-70 years	7	7.78% (n = 7/90)
Gender	Male	79	87.78% (n = 79/90)
	Female	11	12.22% (n = 11/90)
Occupation	Labourer	38	42.22% (n = 38/90)
	Farmer	13	14.44% (n = 13/90)
	Army personnel	12	13.33% (n = 12/90)
	Student	11	12.22% (n = 11/90)
	Housewife	8	8.89% (n = 8/90)
	Shopkeeper	6	6.67% (n = 6/90)
	Government employee	2	2.23% (n = 2/90)
Residence	Rural	50	55.56% (n = 50/90)
	Migrant	37	41.11% (n = 37/90)
	Urban	3	3.33% (n = 3/90)

Table 2: Clinical characteristics of patients			
	Groups	Frequency	Percentage
Duration of disease at presentation	< 6 months	25	27.78% (n = 25/90)
	6-12 months	43	47.78% (n = 43/90)
	1 year – 5 years	22	24.44% (n = 22/90)
	>5 years	0	0
Family history	Yes	9	10% (n = 9/90)
	No	81	90% (n = 81/90)
Type of leprosy	Tuberculoid (TT)	9	10% (n = 9/90)
	Borderline tuberculoid (BT)	30	33.33% (n = 30/90)
	Mid-borderline (BB)	1	1.11% (n = 1/90)
	Borderline Lepromatous (BL)	17	18.89% (n = 17/90)
	Lepromatous (LL)	27	30% (n = 27/90)
	Histioid	5	5.56% (n = 5/90)
	Pure neuritic	1	1.11% (n = 1/90)
Presenting features	Hypopigmented macules/ erythematous plaques or nodules	89	98.89% (n = 89/90)
	Anesthesia/hypoesthesia	54	60% (n = 54/90)
	Spontaneous blistering	19	21.11% (n = 19/90)
	Ulcer	9	10% (n = 9/90)
	Type 1 reaction	12	13.33% (n = 12/90)
	Type 2 reaction	18	20% (n = 18/90)
Nerve involvement	Yes	78	86.7% (n = 78/90)
	No	12	13.3% (n = 13/90)

Table 3: Slit Skin Smear of patients			
	Grading	Frequency	Percentage

Bacterial index	0	10	11.11% (n = 10/90)
	1+	7	7.78% (n = 7/90)
	2+	21	23.33% (n = 21/90)
	3+	24	26.67% (n = 24/90)
	4+	11	12.22% (n = 11/90)
	5+	7	7.78% (n = 7/90)
Morphological index	6+	10	11.11% (n = 10/90)
	<25%	13	14.44% (n = 13/90)
	25-50%	9	10% (n = 9/90)
	50-75%	24	26.67% (n = 24/90)
Grouping	75-100%	44	48.89% (n = 44/90)
	Paucibacillary (PB)	10	11.11% (n = 10/90)
	Multibacillary (MB)	80	88.89% (n = 80/90)

Table 4: Deformity/disability of face, eyes, hands and feet

	Groups	Frequency	Percentage
Occurrence of disability	Yes	42	46.67% (n = 42/90)
	No	48	53.33% (n = 58/90)
Disability of eyes	Redness of conjunctiva	12	13.33% (n = 12/90)
	Lagophthalmos	2	2.22% (n = 2/90)
	Diminution of vision	7	7.78% (n = 7/90)
	Blindness	1	1.11% (n = 1/90)
Disability of hands	Anesthesia	6	6.67% (n = 6/90)
	Claw hand with mobile thumb	11	12.22% (n = 11/90)
	Paralysis of intrinsic muscles	2	2.22% (n = 2/90)
	Wrist drop	1	1.11% (n = 1/90)
	Partial absorption of digits	3	3.33% (n = 3/90)
	Gross absorption (stumps left)	4	4.44% (n = 4/90)
Disability of feet	Anesthesia	10	11.11% (n = 10/90)
	Ulceration	9	10% (n = 9/90)
	Foot drop	0	0
	Resorption of toes	4	4.44% (n = 4/90)
Miscellaneous disabilities	Depressed nasal bridge	2	2.22% (n = 2/90)
	Leonine facies	12	13.33% (n = 12/90)
	Madarosis	6	6.67% (n = 6/90)

Table 5: Distribution of patients as per WHO (1988) grading of disabilities.

	Groups	Frequency	Percentage
Grade 1 disability	Hands	6	6.67% (n = 6/90)
	Feet	10	11.11% (n = 10/90)
	Eyes	12	13.33% (n = 12/90)
Grade 2 disability	Hands	17	18.89% (n = 17/90)
	Feet	13	14.44% (n = 13/90)
	Eyes	9	10% (n = 9/90)
Grade 3 disability	Hands	4	4.44% (n = 4/90)
	Feet	0	0
	Eyes	1	1.11% (n = 1/90)

Table 6: WHOQOL-BREF grading of leprosy patients

WHOQOL-BREF	Median value	Minimum score	Maximum score
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Global perception	49	12	73
Physical domain	42	11	90
Psychological domain	56	7	88
Social relations domain	57	18	82
Environment domain	48	14	76



Figure1: Deformities of feet. a) Callosity, deep fissures and superficial ulcers over heel, b) Bilateral resorption of toes, c)Trophic ulcer and spontaneous blistering, d)Swelling foot, non-healing plantar ulcerover first metatarsal head, with exposed tendons, and hyperkeratotic plaques, e) Scars, ichthyotic skin, brittle nails bilaterally.

Majority of the cases suffering from disabilities/deformities were manual labourers and farmers (57.14%, n = 24/42).

A noteworthy correlation was seen between a delay in diagnosis and the occurrence of disabilities. The median duration of disease at the time of diagnosis, in patients suffering from one or more disabilities, was found to be 15 months as compared to 12 months for rest of the patients.

Out of the total 90 patients, 41 (45.56%) had a time lag of more than 12 months from onset of first symptom till diagnosis. These subjects were found to be afflicted with various disabilities more commonly as compared to those diagnosed within 12 months. Among these 41 patients, 30 (73.17%) were

found to be suffering from one or more disabilities. Out of the 49 patients who were diagnosed within a year of onset, only 12 (24.49%) had one or more disabilities. The difference between the two groups was found to be statistically significant using the chi-square test (p-value = 0.000004).

Among the 42 cases suffering from various disabilities, 41 cases (97.6%) were found to be SSS positive and classified as MB leprosy and only 1 case (2.4%) was SSS negative and classified as PB leprosy. The SSS negative case was categorized into the group of pure neuritic leprosy (PNL).

The assessment of QOL using WHOQOL demonstrated the quality of life to be worst for the physical domain (median 42)

followed by environmental (median 48), global (median 49), psychological (median 56) and social relations domain (median 57). (**Table 6**) When comparing the gender in relation to quality of life, there was a statistically significant difference (p -value < 0.05) in the social relations domain with females having a worse QOL score in this field. Elderly persons were found to have a better QOL, compared to young in the domains of physical and social relationships ($P < 0.04$). Those having more than one and Grade 2 and Grade 3 disabilities at the time of diagnosis had a poor QOL score in all 4 domains than those with single and Grade 1 disabilities ($P < 0.0001$). Factors like socioeconomic status, literacy, and duration of disease were not found to have a significant impact on QOL in any of the domains.

Discussion:

The present hospital based study was conducted with an aim of studying the clinico-epidemiological profile of leprosy and the pattern of disabilities and deformities seen in them. Disabilities and deformities contribute significantly to morbidity and physical challenges in patients. Much of the distress, aversion and social stigma associated with the disease is related to these deformities, mandating early measures to prevent their occurrence through adequate IEC program and early detection through active survey and rehabilitation in afflicted cases.

The mean age of onset of leprosy in our study was 34.46 years which was comparable to that reported previously by Kaur S et al and Atsuro Tsutsumi.^{9,10} The most commonly affected age group was 21-30 years, which is similar to that reported in another study conducted by Raghavendra et al.¹¹ This is a cause for concern as young and productive age group form the most commonly afflicted group. In this study, we documented a clear predominance of male patients comprising 87.78% of cases as compared to 12.22% females, with a male-female ratio of approximately 7:1. There is great variation in reported prevalence of leprosy among males and females with few studies reporting equal incidence among males and females¹², while others record a clear preponderance among males.¹¹ Although leprosy affects both genders, increased incidence among males can be attributed to various social and cultural factors like increased movement among males related to work or otherwise. A conservative setup, especially in rural India, ensures limited mobility and contact with outside world among females, particularly those belonging to low-income low-education groups. The stigma associated with the disease and the fact that leprosy formed a ground for divorce in India until recently further dissuade females from seeking diagnosis and treatment for this disease.¹³

The most commonly encountered type of leprosy was borderline tuberculoid (BT) seen in 33.33% of cases. This was consistent with the previous study conducted by Raghavendra et al.¹¹ The next most common presentation was lepromatous leprosy (LL). Pure neuritic leprosy (PNL) and mid-borderline leprosy (BB) were the least commonly encountered forms

accounting for one case each. This is in contrast to studies from South India where a higher prevalence of PNL has been reported, often times forming the secondmost common presentation after BT leprosy. This might reflect a difference in the epidemiological trend in North as compared to South India.

The median duration of disease at the time of presentation was 12 months. The cases who were diagnosed within 6 months of onset of disease include a meager 27.78%. This is another reason for alarm and apprehension as early diagnosis and treatment might be the most plausible option for limitation of disabilities and physical challenges. This delay in diagnosis may have resulted from a dominant patient profile which encompasses the complex interface of uninformed patients belonging to rural areas with low socioeconomic status, living in close knit communities where cultural beliefs and social stigma play a major role in the choices the patient makes regarding his/her disease. Nonetheless, the failure of puny and inefficient control programmes in effectual screening and early case detection cannot be disregarded.

In this study, we found that a significant majority of our patients (46.67%) were suffering from one or more disabilities and deformities. This was higher than that reported in previous studies by Chavan et al (38.1%) and luqmanahmad et al (41%).^{12,14} The higher occurrence of disabilities in this part of the country may be attributed to delayed diagnosis. Being a low prevalence region, primary care physicians have lesser experience with the varied presentations of leprosy. The delay in diagnosis owing to lack of specialist dermatologists in the primary health care setup has been a significant contributing factor to the development of deformities. The availability of rehabilitative services like micro-cellular rubber (MCR) footwear and reconstructive surgeries in Kashmir has been dismal, to say the least. The gravity can be comprehended by comparing the statistics with those of a state like Gujarat which reports a PR/10000 of 0.36.¹⁵ The MCR distribution in a year is approximately 155 times more in Gujarat in comparison to Kashmir (11007 MCRs versus 71 MCRs) even though the prevalence rate is just 18 times more.^{7,15} On a national level, a total of 52227 MCR footwear were distributed as per NLEP during the year 2015-16.¹⁶ During the same year, 3107 reconstructive surgeries (RCS) were conducted across India at 112 recognized reconstructive surgery centers.¹⁶ On the other hand, J&K does not have any dedicated RCS center and only one RCS was documented in the annual report, performed by an NGO during the year 2015-16.¹⁶

Hands were most commonly afflicted with disabilities (30%), followed by feet (25.56%) and eyes (24.44%). This resonates with the fact that ulnar nerve is the most common nerve to be involved in leprosy and may well be the cause of hands being plagued with deformities. Our findings were similar to those reported by luqmanahmad et al.¹² Redness of conjunctiva, anesthesia of hands and feet, claw hands and ulceration of feet

were among the most commonly encountered disabilities. This was again consistent with the findings of luqmanahmad et al.¹²

In this study, as per WHO grading of 1988, 53.33% of the cases had no disability while grade 1, grade 2 and grade 3 disabilities were seen in 15.56%, 25.56% and 5.55% of patients respectively. Thus grade 2 disability was encountered almost twice as frequently as grade 1 disability. This was more or less consistent with the findings described by luqmanahmad et al and Raghavendra et al, reporting grade 2 disability to be more common than grade 1 disability.^{11,14} The grade 2 deformity rate per million population (3.329) was found to be much better than that of high endemic regions like Chattisgarh (26.74), Odisha (13.24), Delhi (16.04), Dadar & Nagar Haveli (18.72) but not far behind that of other states or the national average of 4.495, despite the fact that the facilities available in our UT lag far behind the rest of the nation.¹⁶ This is another reason for concern as patients who have grade 2 disability must have passed through grade 1 at some point of time since nerve function impairment must occur before visible deformity develops. This indicates a failure of leprosy control and surveillance programme as detection during stages of grade 1 disability could help prevent progression to visible deformities and thus limit physical challenges.

Out of all the patients suffering from disabilities, majority (57.14%) were found to belong to the group of manual labourers and farmers. Impaired sensations in leprosy patients increase their susceptibility towards injuries, burns, etc. Higher incidence of trauma and injuries owing to manual work, as well as neglect of wounds further aggravate the condition in this group of patients. The results were similar to those reported by Raghavendra et al.¹¹ Although another study reported a higher occurrence of disabilities among manual workers and housewives¹², we couldn't document a similar outcome with regard to housewives as they formed a very small chunk of our study population, inadequate to draw any conclusions.

Delay in diagnosis was seen to have a significant relation with the occurrence of disabilities. This is consistent with logic as well as previous reports by Chavan et al.¹²

Almost all the patients suffering with disabilities were classified as multibacillary (97.6%) except for one case (2.4%) which was classified as paucibacillary. A higher bacillary load is consistent with increased nerve affliction and thus a greater incidence of disabilities. This was in contrast to the findings reported by Chavan et al and luqmanahmad et al who stated a higher incidence of disabilities amongst the PB groups.^{12, 14} The comparison is not justified as the definition of PB and MB cases varies widely with authors delineating these groups variously based on number of skin lesions, number of nerves involved, spectrum of leprosy on Ridley Jopling classification, etc. For the purpose of this study, we used SSS as the sole measure to define

PB and MB cases and thus comparison with other studies is not plausible.

In this study, we observed that leprosy had a significant impact on the QOL of patients. The worst impact on the QOL was observed in patients who had Grade 2 and Grade 3, and several disabilities and deformities related to the disease. The impact of leprosy on the social relations aspect of QOL was more predominant in younger persons and female gender, significantly interfering with their ability to socialize. Similar results have been reported in various studies conducted independently by Das NK et al, Bello AL et al, An JG et al.^{17, 18, 19} However, there was no significant impact of age on QoL reported in these studies. Costa MD et al found no impact of age and gender in any of the domains studied. Instead, a better QoL was observed among the married patients, in "home duties" occupation group, and high income group.²⁰

The stigma associated with leprosy is deep seated. The extent of the stigma can be comprehended from the fact that there are 800 odd 'leper colonies' spread across the country which are often cut off from the mainland. Most of these colonies were established in 1890s by British missionaries in order to isolate victims of leprosy and to contain its spread. In absence of permanent treatment for the disease which was known to be highly contagious, victims were taken away from their families and friends to be housed in makeshift colonies. In Kashmir, the patients were housed in a former Mughal fort on the banks of Nigeenlake and the colony continues to exist stigmatizing even the third generations of patients who find it difficult to integrate with the society and are forced to live in seclusion due to government apathy. The colony was initially accessible only by boat and now by road as well.

This is a hospital based epidemiological study on leprosy in our region with an emphasis on the occurrence of disabilities and deformities. Our findings indicate that a large proportion of leprosy patients in our region are already suffering from various disabilities at the time of diagnosis. A delay in diagnosis and treatment, dismal surveillance, ignorance regarding the disease on part of patient as well as treating physician, lack of self-care and poor patient compliance may be the probable reasons for this deplorable affliction. Early diagnosis, initiation of appropriate MDT, health education and adequate training of health staff can go a long way in reducing the burden of physical challenges among leprosy patients. Last but not the least, proper reconstructive surgery (RCS) of deformed treated leprosy patients and their rehabilitation can help them contribute productively to the society and reduce the social, economic and psychological burden of the disease.

Conclusion:

Disabilities and deformities, commonly encountered in our leprosy patients, due to delay in diagnosis and treatment is a

reason for great concern. These deformities of leprosy can have a significant physiological, psychological, economic and social impact on the patient. Early diagnosis, adequate treatment, RCS and rehabilitation can be achieved through successful NLEP implementation along with an efficient primary healthcare system, surveillance schemes and self-care practices.

Source of conflict: Nil

Acknowledgement: Nil

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