

A Study on Clinical Profile and Disability and Deformity among Newly Diagnosed Leprosy Patients Attending a Tertiary Care Institution

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After the widespread leprosy campaign, the prevalence of leprosy cases is coming down that shifts priorities towards finding deformities and disabilities occurring due to leprosy. This study was done to estimate the prevalence of deformity and disability and to study their clinical pattern in newly diagnosed leprosy cases. A cross-sectional study was conducted in the outpatient Department of Dermatology of a Tertiary Care Centre from January 2015 to December 2020. A total of 102 newly diagnosed leprosy patients were included after thorough examination and investigations. Data collected was analyzed, and total deformity found was 75.49% (Grade 1 + Grade 2 deformity). Males were affected more (53.92%) than females (46.08%). The proportion of Grade 2 deformity (G2D) in our study was 27.4% (n=28), including madarosis, trophic ulcer, claw hand, absorption of fingers etc. The most usual form of deformity found was madarosis (10.78%), and most common age group affected was 21-30 years (26.47%). The most common type leprosy-affected was Borderline Tuberculoid (27.45%). 50% of our cases presented at our centre between 6-12 months and 28.43% after 12 months of appearance of symptoms. This delayed reporting and a high proportion of deformities in our study as well as in the programme of this Surendranagar district suggest that for this area it is high time to put effective measures for increasing the efficacy of the existing healthcare system for early diagnosis and treatment of G1D to prevent it from converting into G2D.

Keywords : Leprosy, Deformity, Disability, Cross-sectional study

Introduction

The word leprosy is derived from the Greek word "lepros" which means "scaly". The Indian word "kushtha" is derived from the Sanskrit word "kushnati" which means eating away.

Hansen's discovery of *Mycobacterium leprae* in Norway in 1873 represented one of the first identifications of a microbial pathogen of man. *M. leprae* is an obligatory intracellular parasite with a special affinity for Schwann cells and cells

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of the reticuloendothelial system. Leprosy is a multisystem disease in which *M. leprae* and inflammatory cells infiltrate skin, nerve and various internal organs, including liver, kidney, eye, nasopharynx, larynx, testes, etc. Leprosy can manifest with gross disabilities, deformities and mutilations. Even at present, great human suffering and a substantial loss of human resources result from the development of deformities in an overwhelming number of leprosy patients.

The registered global prevalence of leprosy was 1,92,713 cases (0.25/10,000 population) at the end of 2017, increasing by 20,765 over that in 2016 (WHO 2018). India has reported a decrease in the number of new cases since 2016, by nearly 15,000 cases (1,35,485 in 2016 to 1,20,334 in 2017-2018). Globally the number of new cases detected has decreased by 15% over the past 10 years (WHO 2019).

Disability has also been defined as a deterioration of one's ability or capacity to perform a function normally. On the other hand, Deformity is an alteration in the form, shape, or appearance of the affected part of the body. Globally total number of 14,322 new cases with Grade 2 Deformity were reported in 2009 and 11,323 in 2018, a decrease of 21% in 10 years. Together, the 23 global priority countries accounted for 90.2% of new Grade 2 Deformity cases globally. The number of new Grade 2 Deformity cases in India has reduced from 5245 in 2017 to 3666 in 2018 (WHO 2019).

In the current scenario, many leprosy patients come with deformities as a chief concern, rather than skin lesions. Thus we conducted this study to understand the situation pertaining to disabilities and deformities among the newly diagnosed leprosy cases in our district. This study was carried out in a tertiary care hospital to estimate the prevalence of deformity and

disability and to study the clinical pattern in newly diagnosed leprosy cases that may help in moving forward to tackle the problem at community level.

Material and Methods

This was an open cross-sectional study performed at the Outdoor Patient Department of Dermatology at a Tertiary care hospital (C.U. Shah Medical College and Hospital) in a district of Gujarat. The study population included all newly diagnosed leprosy patients at the outdoor patient department during a total period of 6 years from 2015 to 2020. Patients with pre-existing disability of some other known disease than Hansen's disease were excluded. All patients developing deformities after starting Multi-drug therapy (MDT) were excluded.

Data of all newly diagnosed Hansen's patients were noted, including history, general and systemic examination, cutaneous examination, nerve palpation, sensory and motor function assessment, slit skin smear, Biopsy findings.

Approval from the Ethical Committee and consent of the patients were taken for data collection and publication.

WHO Disability Grading system (Brandsma & van Brakel et al 2003) was used :

Hands and Feet:

Grade '0' - No anaesthesia, no visible deformity or damage.

Grade '1' - Anesthesia present, but no visible deformity or damage.

Grade '2' - Visible deformity or damage present.

Eyes:

Grade '0' - No eye problem due to leprosy, no evidence of visual loss.

Grade '1' - Eye problem due to leprosy present, but vision not severely affected.

Result of this (vision 6/60 or better: can count fingers at 6 meters)

(Distance, corneal sensation testing-optional).

Grade '2'- Severe visual impairment (vision: worse than 6/60: Inability to count fingers at a 6 meters distance), also includes lagophthalmos, irido-cyclitis and corneal opacities.

Data analysis was done according to age, gender, occupation, type of leprosy, type of deformity, grade of disability, presence of lepra reaction, using R programming software.

Results

During this study period from 2015 to 2020, a total of 102 patients of newly diagnosed with leprosy, presented at the outdoor patient department of our tertiary care centre were examined, and data was recorded.

The age of these cases ranged from 13 to 80 years. The majority were in the 21-30 years, 26.47% (n=27) followed by 31-40 years, 19.60% (n=20). In our study, the most common form of livelihood was found to be the manual labourers, 54.9%

(n=56) including rickshaw-puller, mason, barber, carpenter, agricultural labourer and rest included into others, 45.1% (n=46) category like a student, office worker, businessman, clerk (Table 1).

Out of 102 cases as per Ridley-Jopling classification (Ridley & Jopling 1962, Ridley & Jopling 1966) and Indian classification of leprosy 1982 (IAL 1982) the spectrum of leprosy showed a majority of the patient into BT, 27.45% (n=28) and LL 20.58% (n=21).

Information about duration of disease at the time of reporting is provided in Table 2. It was seen 50% reported between 6-12 months and 28.43% after one year of appearance of the symptoms. Comparison with national programme data of Surendranagar district is done in Table 3 whereas comparative analysis with other published studies is presented in Table 4.

Profile of deformities seen in our cases is shown in Fig. 1. The most common form of leprosy associated with deformities are BT and LL in our

Table 1 : Gender, age and occupation wise distribution of cases

	GRADE 0	GRADE 1	GRADE 2	Number of cases (N=102)
Grade	24.5%(n=25)	48%(n=49)	27.4%(n=28)	
Gender				
Male	13.72%(n=14)	24.5%(n=25)	15.68%(n=16)	53.92%(n=55)
Female	10.78%(n=11)	23.52%(n=24)	11.76%(n=12)	46.08%(n=47)
Occupation				
Manual	11.76%(n=12)	25.49%(n=26)	17.64%(n=18)	54.9%(n=56)
Others	12.74%(n=13)	22.54%(n=23)	9.80%(n=10)	45.1%(n=46)

Table 2 : Duration of disease

Duration	No. of patients	percentage
Less than 6 month	22	21.57%
6 months to 1 year	51	50.00%
More than 1 year	29	28.43%a

Table 3 : Comparison of this study with district data of Surendranagar (2015-2020)*

Indicators	State figures of Surendranagar District	This Study
New cases	170	102
MB cases	150 (88.23%)	102(100%)
Female cases	70(41.18%)	46(45.1%)
Child cases	09(5.30%)	01(0.98%)
Male cases	91(53.53%)	55(53.92%)
Male : Female Ratio	1.3 : 1	1.2 : 1
Grade 2 deformity	23(13.53%)	28(27.4%)
≤ Grade 1 deformity	147(86.47%)	74(72.55%)

*District state figures of Surendranagar were collected from District Leprosy Office at Surendranagar (2021).

Table 4 : Comparison of data of present data with published studies

	Our study	Reyila et al (2019)	Rathod et al (2020)	Mangala et al (2019)	Raghavendra et al (2017)
Total no. of patients	102	76	200	113	50
M/C age	21-30 years (26.47%)	-	-	31-40 years (25.66%)	21-30 years (20%)
Gender					
Male	53.92%	75%	67%	63.71%	78%
Female	46.08%	25%	33%	36.28%	22%
Occupation					
Manual	54.9%	-	-	-	-
Others	46%	-	-	-	-
Grade of disability					
1	49%	17.1%	21.25%	16.81%	26%
2	27.4%	31.6%	6.31%	83.18%	74%
Type of reaction					
Type 1	10.78%	13.15%	-	-	10%
Type 2	10.78%	1.31%	-	-	14%
Type of deformity (M/C)	Madarosis 10.78%	Claw hand 13.15%	Trophic ulcer of hand or foot 29.34%	Trophic ulcers 37.16%	Claw hand 38%
Type of leprosy (M/C)	BT 27.45%	BT 51.3%	LL 30.5%	BT 38.05%	BT 34%

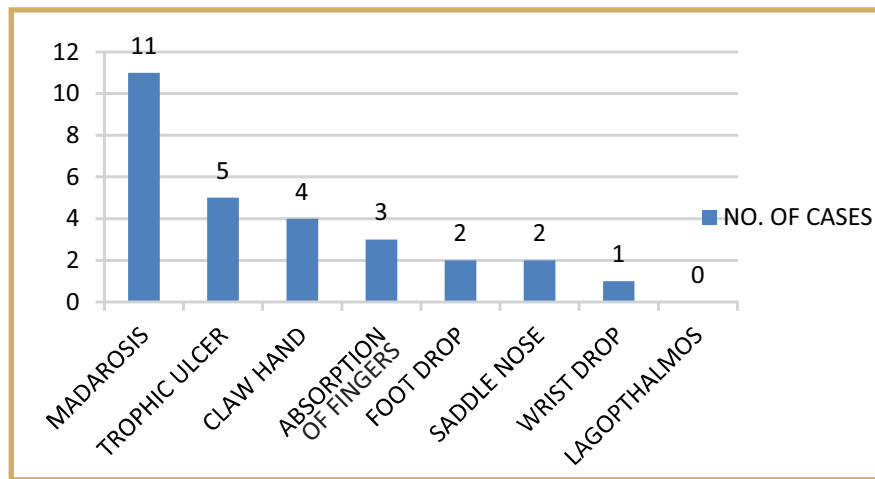


Fig. 1 : Types of deformities observed in the leprosy patients

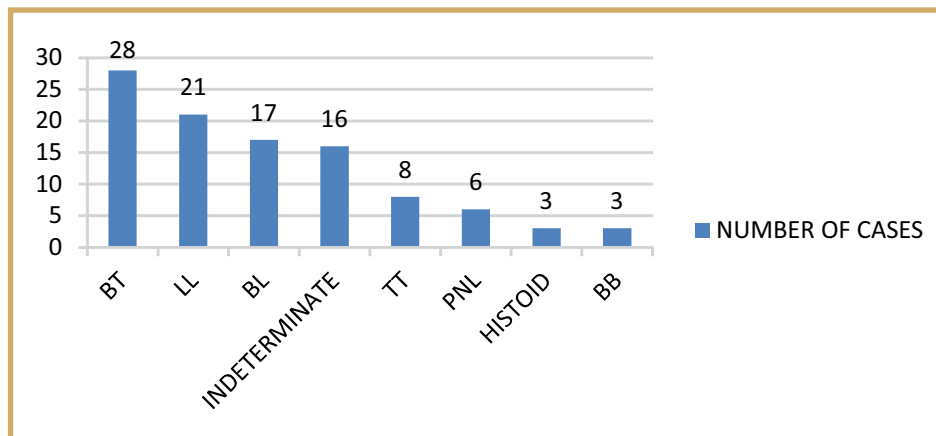


Fig. 2 : Spectrum of Leprosy observed among leprosy patients

(Abbreviations: BT-Borderline Tuberculoid leprosy, LL-Lepromatous leprosy, BL-Borderline lepromatous Leprosy, TT-Tuberculoid leprosy, PNL- Pure Neuritic Leprosy, BB- Borderline Leprosy)

study (Fig 2). Different types of deformities seen are presented in Figs. 3 to 8.

As per WHO disability grading system (Brandsma & van Brakel 2003) most common grade of disability found was grade 1, 48% (n=49) followed by grade 2, 27.4% (n=28) and 25 patients (24.5%) presented without anesthesia (grade 0). Most

common form of deformity observed in our study were madarosis (loss of lateral 1/3 of eye brow, Fig. 3) 10.78% (n=11) followed by trophic ulcer (Fig. 4): 4.9% (n=5), claw hand (Fig. 5): 3.92% (n=4), absorption of fingers (Fig. 6): 2.94% (n=3), foot drop (Fig. 7): 1.96% (n=2), saddle nose (Fig. 8): 1.96% (n=2), wrist drop: 0.98% (n=1).



Fig. 3 : Madarosis over right eyebrow



Fig. 4 : Trophic ulcer over right sole



Fig. 5 : Claw hand deformity



Fig. 6 : Absorption of right sided fingers



Fig. 7 : Right sided foot drop



Fig. 8 : Saddle nose

Out of 102 patients in our study, the total number of patients presenting with lepra reaction was 10.78% (n=11) in both Type 1 and Type 2 reactions.

Discussion

Disability and deformity associated with leprosy remains a major hindrance affecting the quality of life of a patient. All available data regarding disabilities and deformities are essential for understanding these complications better and finding new implementations possible in existing disease control programmes.

India eliminated leprosy as a public health problem (less than 1/10,000 prevalence) in December 2005. The prevalence of leprosy in

India (2017) was 0.66 per 10,000 population, with an annual case detection rate of 9.71 per 1,00,000 population. In India, due to NLEP (National Leprosy Eradication Programme), a total of 34 states and union territories achieved elimination of leprosy with a cure rate of 90-95% (Park 2018a, Park 2018b, NLEP 2017).

As now the elimination target has been achieved, priorities have been shifting from providing leprosy treatment to the prevention of leprosy complications, especially disabilities and deformities caused by leprosy.

As the theme of world leprosy day-2020 was ending leprosy related stigma and discrimination will enhance early case detection and help us

achieve a leprosy free world. The evidence is clear that stigma creates fear, fear inhibits health-seeking, delayed health-seeking causes late diagnosis, late diagnosis can cause deformity and disability (WHO 2020).

The international classification of disabilities, handicaps, deformities includes various definitions. *Disability* is defined as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. The affected person finds it unable to perform some activities at home or workplace (Kumar et al 2004). On the other hand *handicap* is an disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a normal role for that individual (Kumar et al 2004). The affected person may lose their jobs, earning capacity and social rejection. Srinivasan & Noordeen (1966) defined *deformity* as any loss or abnormality of a psychological, physiological or anatomical structure or function. Deformities may be either visible impairments or consequences of invisible impairments. Considering the above international definitions, the total number of patients having deformity in our study was 75.5% (n=77), out of which 30 patients (29.4%) were unable to perform their routine work as before (disability) that included manual labourers, a rickshaw puller, mason, barbers etc. Out of 30 disabled patients, 10 patients (9.8%) had to lose or change their occupation due to their limitation, e.g. mason could not hold a brick due to hand deformity.

Global leprosy strategy 2016-2020 had envisaged the following targets (WHO 2016) :

- 1) Zero number of children diagnosed with leprosy and visible deformities.
- 2) <1 per million rates of newly diagnosed leprosy patients with visible deformities.

- 3) Zero number of countries with legislation allowing discrimination on the basis of leprosy.

Table 3 shows the comparison of our study with State Figures of our District (Surendranagar) for the year duration of 2015 to 2020.

The ratio of male to female patients in our study is in accordance with State Figures 1.2:1 and 1.3:1, respectively. Child cases observed in State figures was 5.3% (n=1) when compared to our study, 0.98% (n=1). Grade 2 deformity observed in State Figures of our district was 13.53 % (n=23) and total patients presented with Grade 1 deformity or less were 86.47% (n=147) whereas in our study, it was 27.4% and 72.55 %, respectively.

In a study conducted by Rao et al (2020), results were similar to our study, with total new leprosy patients being 1680, Male to Female ratio was 2.1 : 1, and Grade 2 deformity patients out of new leprosy patients were 17.79% (n=299).

The study conducted by Nayak et al (2017) showed that the majority were male, 72.3%, male and 27.7% female. In his study, Daniel et al (2019) reported that the majority were male, 69.4% than female 30.6%. In our study, the majority affected were males 53.92% as compared to females 46.08%; the data in our research is in accordance with data reported in various previous studies. Males are affected more as compared to females generally in the proportion of 2:1 (Joshi 2016). Raised occurrence in the male may be due to more exposure and chance to working outside and female playing role as a homemaker, especially in rural India. Another reason may be that in rural areas, females are hesitant to come forward for diagnosis.

In the study conducted by Nayak et al (2017) majority were in the age group of 41-50 years (27.2%), followed by 31-40 years (18.4%) age group. In another study by Kar et al (1984), 60%

were aged above 40 years, and 40% were in 21-40 years of age group. In our study, the majority affected age group were 21-30 years (26.47%) followed by 31-40 years (19.6%). In our study, no patient is in the age group of 1-13 years. The majority of patients come in between the age group of 13 to 80 years.

In the study conducted by Daniel et al (2019), the majority of patients were manual labourers like farmers and construction workers with (70.1%) followed by housewives with (16.1%). Withington et al (2003) also reported that the most affected were manual labourers (18.2%) as compared to others (11.9%). In our study, most patients were manual labourers 54.9% compared to other occupations 46%. So, the data in our study is similar to the data recorded in study as mentioned earlier. Loss of sensory function is an inevitable consequence of leprosy. Having to work with hands and feet, labourers were the most common patient group showing deformities, then the others.

The study conducted by Nayak et al (2017) showed that the majority of the study population (60.86%) had WHO grade 1 deformity and (39.13%) had WHO grade 2 deformity. In the study, Sarkar et al (2012) showed similar prevalence in Grade 1 deformity and Grade 2 deformity. In our study, Grade 1 deformity was 48%, followed by Grade 2 deformity 27.4%. In leprosy, hands, feet, the eye remains commonly affected areas of impairment, and their impairment significantly affects day to day routine activity. For that reason, they are included in the WHO grading system (Brandsma & van Brakel 2003). In our study, a total of 75.4% (Grade 1+ Grade 2) deformities were observed at the time of diagnosis of the patient, which is a very high proportion. One of the reasons could be that this study was conducted at a tertiary care centre where patients come late, i.e., after the deve-

lopment of complications. Mangala et al (2019) and Rathod et al (2020) have reported similar findings specially regarding the trophic ulcers.

Out of 102 patients, 88.2% patients (n=90) had taken some form of oral and topical medication, and none of them had taken MB or PB leprosy pack at any point in time. 29 patients (28.43%) had disease for more than 1-year duration before being diagnosed (Table 2). The reason behind the high proportion of deformity in newly diagnosed patients may be due to delay in registration, lack of effective screening & occupation like labourers. All grade 2 deformities must have passed through grade 1 deformity, so more emphasis should be put on finding the Grade 1 deformity early and prevention from converting into grade 2 deformity by effective measures such as, 1) Good selfcare of hands & feet, like daily checking for injuries or new lesion, always use chappal or any footwear for walking. 2) Eyecare. 3) Change occupation if necessary. The management of grade 2 deformity will need physiotherapy for motor deformities and surgical correction in suitable patients.

It was observed that some patients also presented with more than 1 type of deformity. A study conducted by Srinivasan (2000) showed that the most common deformity was claw hand 21.5%. A survey conducted by Sow et al (1999) also reported that 33% had claw hand deformity in their study. The study Nayak et al (2017) reported that trophic ulcer was the most common deformity 21.73%. In our study most common deformity observed is madarosis 10.78%. However, 66 cases were classified in BT, LL, and BL types; thus, it is possible to have madarosis more noticeable. Nevertheless, it is a pointer to the proper examination of facial deformities.

In an epidemiological study of leprosy (Kumar et al 2001, Schipper et al 1994), the most usual form of leprosy was BT 30.5%. In our study, the

most usual form of Leprosy is BT 27.45%. So, the findings of our study are similar to above-mentioned study. The reason behind the high proportion of deformity in BT type of leprosy could be due to 1) BT form is the most common type of leprosy (WHO 2003) and 2) large compact granuloma formation in BT creates continuous pressure over nerve fibers at sites ultimately causing damaged nerves. Table number 4 shows a comparison of this study with several other studies.

The deformities and disabilities in leprosy warrant its control at every level of preventive medicine and its correction, wherever possible, through surgical procedures.

Rehabilitation and reintegration of patients in society can only be achieved by the sustained efforts of the patients, the health care staff, and society as a whole. It is necessary to make the most of the patient's abilities rather than focusing on their disabilities. This can be achieved more effectively through a community-based approach than through the traditional institution-based approach, which is not only highly expensive but often inappropriate in a local setting.

Limitation of study

One of the limitations of our study was the fact that it was conducted in a tertiary care centre, patients with the severe disease tend to attend the tertiary care centre, which may be the reason of the high proportion of deformity 75.4% (Grade 1 deformity+ Grade 2 deformity). One of the other limitations was the study sample size, which was small containing 102 new leprosy patients. A larger sample size, study period and large geographical area would give a better understanding of the prevalence of deformities and disabilities.

Conclusion

Our study concluded that risk factors causing disability in leprosy patients are age (21-30), gender (male), occupation (labourers) and tuberculoid spectrum of leprosy.

In our study, 75.49% (n=77, grade 1 + grade 2 deformity) patients presented with deformity at the time of diagnosis. Early diagnosis of Nerve function impairment (NFI) will prevent progression of Grade 1 deformity to Grade 2 deformity. So as leprosy prevalence is coming down, the primary focus should be searching for Grade 1 deformity leprosy patients as early as possible.

We would recommend further studies with a larger sample size, involving bigger geographical areas, collecting all data related to deformities and disabilities associated with leprosy at the time of the first diagnosis, during the multi-drug therapy (MDT) and even after release from treatment (RFT) with follow up visits. These data will give us a comprehensive idea to understand factors precipitating disability which may help us implement new measures to prevent and reduce the occurrence of deformity and disability in leprosy patients.

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