

Disability Status of the Leprosy Patients Enrolled in a Tertiary Health Centre in a Metropolitan City

V Anjum¹, MSK Swarupa², R Neeluri³

Received : 12.06.2016 Accepted : 16.12.2016

Study of disabilities in leprosy remains an important aspect as these lead to daily activity restrictions, loss of job, financial constraints, psychological burden, personnel and social stigma. This study has been carried out to study the socio-demographic profile, socio-cultural aspects and various Disability prevention and medical rehabilitation services available for the leprosy patients in the health centre in a South India urban settings. It is descriptive cross-sectional study carried out at tertiary health centre at Hyderabad, Telangana, South India for three months during September to November 2015. A semi structured questionnaire was used to get complete information about the disease, treatment, disability and services utilized by the patients. A total of 54 leprosy patients were enrolled which included 68% males and 32 % females. 2/54 (3.7%) were children. Multibacillary type was seen in 94.4% and slit skin smears were positive 35% of patients had positive for acid fast bacilli (AFB). Deformities were presenting complain in 18/54 (33.3%) patients, another 11 had disability before coming to the facility but it was not possibly main concern., thus in 29/54 patients (53.7%) the deformity developed before starting MDT. 57% of patients felt benefitted from Disability Prevention and Medical Rehabilitation (DPMR) services. While the patients studied cannot be considered as representative of patient population in this city or region, development of deformities before start of MDT indicates delayed diagnosis in a section of society. Similarly a big proportion of patients' disabilities despite MDT indicates the need for improvement in management practices for reactions and nerve damage.

Key words: Disabilities, self-reporting leprosy cases, tertiary care centre, Hyderabad

Introduction

Leprosy affects the peripheral nerves and skin. Nerve damage caused by the *M leprae* leads to loss of sensation, weakness of the muscles and autonomous functional loss. This in turn results in the disabilities and deformities in leprosy patients. India contributes approximately 70% of the new cases detected globally as reported in

2011 (WHO 2012). A total of 5256 Gr. II disability detected amongst the New Leprosy Cases during 2013-14, indicating the Gr. II Disability Rate of 4.13 / million population in India (NLEP 2013-14).

Among communicable diseases, leprosy remains a leading cause of peripheral neuropathy and disability in the world, despite extensive efforts to reduce the disease burden (Mathews et al 2007).

¹ Dr Vaseem Anjum, MBBS, PG student

² Dr MSK Swarupa, MD, Professor

³ Dr Rajesh Neeluri, MD, Assistant Professor

Community Medicine Department, Deccan College of Medical Sciences, Hyderabad, Telangana, India

Correspondence: Dr Vaseem Anjum e-mail : vaseemanjum8@gmail.com

These disabilities have serious psycho-social impacts on their lives. Leprosy disabilities are preventable by early diagnosis, timely treatment and proper services for prevention of disability.

The Disability Prevention and Medical Rehabilitation (DPMR) guidelines were launched in 2007 in India. In 2009, the World Health Organization (WHO) launched the "Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy for 2011-2015". The target was to reduce the number of new cases of leprosy with Grade 2 deformities (G2D) per 100 000 total population (G2DR) by at least 35% between the end of 2010 and the end of 2015 (Alberts et al 2011).

An efficient leprosy eradication / elimination programme should detect cases early (preferably before they get any deformity) and those who get it should be benefitted by DPMR services. It has been suggested that leprosy patients with grade 2 disability (G2D) should be used as a monitoring tool of the results of leprosy control activities (Durrheim and Speare 2003, Smith and Richardus 2008, Malviya 2014). Despite various efforts, in a study reported from a South India referral hospital half of the newly diagnosed leprosy patients had disability (Bhat and Chaitra 2012). Such examples show disconnect between patients and services in some places. These deformities may lead to social discrimination, economical constraints and loss of confidence among patients.

There is very little data on the types of problems faced by people with leprosy - related disabilities (PLD) and the resulting needs they have for services (Malaviya 2014).

This preliminary study aims to understand the burden of the disabilities in leprosy cases reporting to a Tertiary Care Specialized centre working on leprosy and their impact on socio-cultural aspects of life of leprosy patients. Besides the socio-demographic profile and socio-cultural

aspects of the leprosy patients enrolled, this study attempts to analyse their disability status and the various Disability prevention and medical rehabilitation (DPMR) services availed by the patients.

Patients and Methods

It is an institution based descriptive cross-sectional study done at Shivananda Rehabilitation Home, Hyderabad, Tertiary Health Centre for the leprosy patients in urban area of metropolitan city. This centre provides diagnostic and treatment facilities. It also caters surgical correction for the deformities, physiotherapy and rehabilitation services. Newly registered leprosy patients during three months (September to November 2015) of study were included. They were interviewed using a pre tested semi structured questionnaire regarding disability, the socio-cultural aspects and services availed after obtaining informed consent. Patients not willing to participate were excluded from study.

Patients registered at this centre for the first time during this period and who consented to be part of study, were examined clinically, and tested for Bacterial index using Slit skin smear test and then a complete neuromuscular assessment done as a routine for diagnosis and management.

WHO definitions and disability grading system (Brandsma and van Brakel 2003, WHO 2009) was followed for the study. (Table 1)

The highest grade of disability of any of these body sites is used as an overall indicator of the disability status of a person with leprosy.

The data was analyzed using appropriate statistical tools.

Results

During the study period, a total of 54 leprosy patients registered newly in the centre. Socio-demographic profile of these cases is presented in Table 2.

Males are 37 (68%) and females 17 (32%) in number. Hindus were predominant, 49 (90.74%). While equal number were observed in never married and currently married, 26 (48.15%), the divorced were 2 (3.7%). 44.44% patients were illiterate. Majority (57.41%) of the study group

Table 1 : WHO grading system used in the study

Disability Grade	Hands and feet	Eyes
Grade 0	No anaesthesia, no visible deformity or damage	No eye problem due to leprosy; no evidence of visual loss
Grade 1	Anaesthesia present, but no visible deformity or damage	Eye problems due to leprosy present, but vision not severely affected as a result (vision: 6/60 or better; can count fingers at 6 meters).
Grade 2	Visible deformity or damage present	Severe visual impairment (vision worse than 6/60; inability to count fingers at 6 meters); also includes lagophthalmos, iridocyclitis and corneal opacities

Table 2 : Socio demographic profile of the study group (n=54)

Demographic Characteristics	Frequency	Percentage	
Gender	Male	37	68.52
	Female	17	31.48
Religion	Islam	5	9.26
	Hinduism	49	90.74
Marital Status	Never Married	26	48.15
	Currently Married	26	48.15
	Others	2	3.7
Educational Status	Illiterate	24	44.44
	Primary School	6	11.11
	High School	10	18.52
	Intermediate	5	9.26
	Graduate	8	14.82
	Post graduate	1	1.85
Occupation	Unemployed	13	24.07
	Unskilled	31	57.41
	Semi-skilled	5	9.26
	Skilled	1	1.85
	Professional	4	7.41
Socio-Economic Class	Upper	2	3.7
	Upper Middle	6	11.11
	Lower Middle	4	7.41
	Upper Lower	39	72.22
	Lower	3	5.56

were unskilled workers. Upper lower socio-economic class were 72.22% among the patients (Table 1).

There were 2 (3.7%) in the age group of below 15 years. Almost 40 (74%) are between the age group of 16 years to 45 years, while 12 (22%) are 46 years and above (Table 3). The mean age was 33.8 years.

Patients presenting with complaints of hypopigmented anaesthetic skin patch were 16.7%, with reactions 25.9% and deformities 33.3% (Table 4).

As per WHO classification, 51 (94.4%) patients were classified as Multibacillary. While 36 were started on Multidrug Therapy (MDT) at the centre as per NLEP guidelines, others had been on treatment before registering at this centre 8 patients had defaulted. The other 3 were paucibacillary and all of them had completed the MDT treatment with no defaulters.

The slit skin smear was positive for acid fast bacilli (AFB) in 35% patients and the bacterial index

varied from 0.33 to 6.0)

Of the 54 leprosy patients, 48 had some type of disability. While there were no defaulters among PB cases, 8 patients among MB had defaulted. 45 patients with MB type and 1 patient with PB type of leprosy had Grade 2 Disability (G2D) respectively.

The occurrence of disability with respect to the multidrug therapy in the study group was 53.70% before starting the treatment, during the treatment 22.22% and after treatment 12.96% (Fig 1).

Table 3 : Age distribution of leprosy patients included in the study included

Age in years	Frequency	Percentage
0-15	2	3.70
16- 30	26	48.15
31-45	14	25.93
46-60	10	18.52
≥ 61	2	3.70
Total	54	100

Table 4 : Presenting complaints of the patients

Presenting Complaints	Frequency	Percentage %
Hypo pigmented hypo anaesthetic skin patch	9	16.7
Nodules	1	1.9
Pure neurotic type - loss of sensation	3	5.6
Type I or Type II reactions	14	25.9
Deformities	18	33.3
Ulcers	9	16.7
Total	54	100

Table 5 : Disability Grading seen in the patients

Disability Grading	Hand		Feet		Eye	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Grade 0	12	22.2	29	53.7	52	96.3
Grade 1	4	7.4	11	20.4	-	-
Grade 2	38	70.4	14	25.9	2	3.7
Total	54	100	54	100	54	100

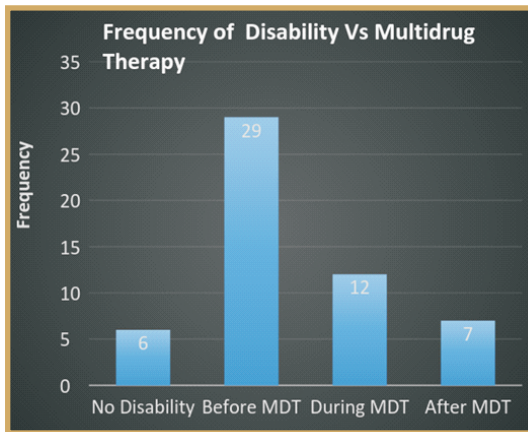


Fig 1 : Frequency of disabilities in relation to MDT.

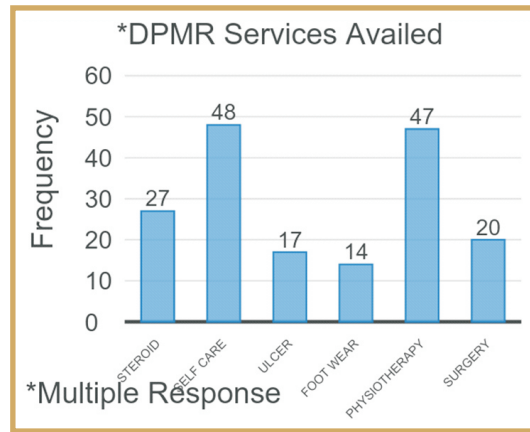


Fig 2 : DPMR Services provided to patients

Table 6 : Frequency of ulcers, neuritis and reactions in study group

Complications in the leprosy patients		Frequency (%)
Ulcers		17 (31.5)
Hand		9 (16.7)
Feet		6 (11.1)
Both hand & foot		2 (3.7)
Single		9 (16.7)
Multiple		8 (14.8)
Simple		5 (9.3)
Complicated		12 (22.2)
Neuritis		11 (20.4)
Reactions		
Type I		3 (5.6)
Type II		6 (11.1)

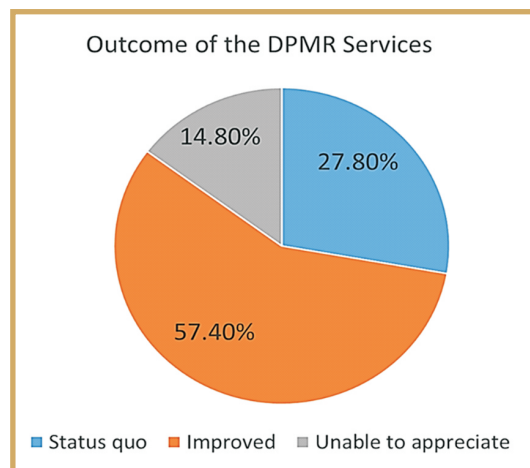


Fig 3 : Perceived benefit of the DPMR Services felt by patients

The leprosy patients included in the study had deformities of hand, feet and eyes (Table 5). Total 48 (88.89%) study subjects had disabilities, where 3 of them had paucibacillary type of leprosy. More than one deformity was seen in 22 (40.74%). Deformities in the hand were seen in 38 (70.4%), in feet 14 (25.9%) and in eyes only 2 (3.7%).

The EHF score varied from 1 to 12 where majority, that is 17 (31.48%) patients had score of 2.

Ulcers, neuritis, Type I and Type II reactions were the complications seen in the study group. Ulcers (31.5%) were the most common complication seen. Most ulcers were complicated, single and seen more commonly on hand. Other complications seen in patients were neuritis (20.4%), Type I (5.6%) and Type II (11.1%) reactions (Table 6).

The disability prevention and medical rehabilitation (DPMR) services provided to the patients

Table 7 : Social and Self Discrimination

Social Discrimination		Self-discrimination*	
Isolation from gatherings	(7) 12.96%	Fear of divorce	(19) 35.19%
Divorce	(2) 3.7%	Do not want to marry	(2) 3.7%
Separately kept in home	(5) 9.26%	Fear of transmitting to others	(23) 42.59%
Removed from school	(3) 5.56%	Uncomfortable with question asked by people	(19) 35.19%

*Multiple response

at the centre were ulcer dressing, self-care practices, steroids for reactions, physiotherapy, special footwear and surgical corrections of the deformities (Fig 2). The self-care practices and physiotherapy were the services availed most by the leprosy patients. Improvement in the condition was appreciated by 57.4% while 14.8% were not sure if the services had any effect on their condition. Remaining 27.8% said there was no change in their condition (Fig 3).

The patients enrolled also face social discrimination due to the visible disabilities and complications (Table 7). In the study group 31.48% faced social stigma and 55.55% had self-discrimination. 35.19% were living with fear that their spouse may divorce them because of the presence of the disease. A small number (3.7%) also revealed that they do not want to marry due

to their disease. Most of the patients (42.59%) feared transmission of the disease to others and avoided the social gatherings though their close associates did not show discrimination. 35.19% patients also shared the fact that they feel embarrassed when asked about their disease in the family and social gatherings and thus restrict themselves from attending them.

While 63% of disabled patients were independent in their daily activities, 37% needed some assistance due to restricted activities as a result of the deformities. This also had effect in attending the work daily (Table 8)

Discussion

The present study shows that the people effected by leprosy are suffering from disabilities despite the extensive efforts of government to eliminate the disease. These disabilities and deformities have strong impact on the personal and social life of the patients.

A study in Maharashtra (Asia 2015) had 13.1% children between 0-15 years, while in the study had 3.7% children, indicating that there is still transmission of disease.

In the present study the G1D and G2D in hand were 7.4% and 70.4%, feet 20.4% and 25.9% respectively. In eye 3.7% G2D was seen. The high percent of hand deformities can be related to the fact that this referral centre where study was performed, had specialized hand surgeon and patients were referred from peripheral centres

Table 8 : Loss of days at workplace due to leprosy

Absent from work in days per year	Frequency	Percentage
0	8	14.8
10	1	1.9
120	1	1.9
180	2	3.7
20	2	3.7
365	1	1.9
30	38	70.4
7	1	1.9
Total	54	100

for surgical corrections. The disability rate in a study done in Pondicherry (South India) was 16.23% (Reddy and Bansal 1984). In a study from West Bengal, 20.1% had disability, among which 11.5% had grade-1 (loss of sensation) and 8.6% had grade-2 (visible deformity) disability (Sarkar et al 2012). Much higher grade 2 disability in our study group may suggest biased sampling or delay in accessing leprosy services by a section of people in this area.

The findings of disability before treatment was high (53.7%) in present study which was in accordance with other studies. In the study of Van Brakel et al (2012) 51% G2D was associated with MB patients. Study done by Asia et al (2015) had Grade I disability 24% and Grade II disability as 58.4%.

The study of van Brakel et al (2012) recorded disabilities of feet in 47%, followed by 31% in hands and 11% in eyes. Disability of hand was 63.4%, feet 29% and 7.3% of cases had both hand as well as feet disabilities in study reported by Asia et al (2015). No visual impairments were recorded in this study.

In present study the improvement was felt by 57.4% of patients, however, this should be assessed by objective criteria. This could be due to subjective perception of patients and it was too early to physically find difference in short time of our study period. In total 26% of those with grade 1 or 2 at diagnosis improved in the study of Van Brakel et al (2012). Another study done in Bangladesh showed 15.2% of disability (G1D or G2D) at the time of registration (Withington et al 2003). The study carried out in Bangladesh observed patients had a spontaneous sensory nerve function improvement rate of 62% and a motor nerve function improvement rate of 33% at 12 months from onset of NFI (Croft et al 2000). These experiences indicate the need of in-depth analysis before coming to any conclusion about

benefits.

In our study 67% had restriction in daily activities, which is comparable to 60% in the study of van Brakel et al (2012). Future studies should focus on methods to overcome this problem.

In this study it was 31.48% for social stigma and 55.55% for self-discrimination. In a study done in China 4.4% of study group were isolated by community and 33.5% were not living with their other family members (Shumin et al 2003). 35.5% expressed that they experienced stigma in another study (van Brakel et al 2012).

This study brings out findings which are a matter of concern, but should be confirmed by well designed studies. The male predominance does not rule out the disease burden in females, it may reflect the health seeking behavior in women. This needs to be studied further. 3.7% of children with disability indicates transmission in community and need for contact screening. Younger age patients with deformities are alarming and need immediate attention. Though MB cases had more disability, the one PB case with G2D disability suggests that early case detection and timely treatment is important for cases across the spectrum. The patients presenting with deformities and associated complications indicate lack of awareness or stigma which has to be addressed to prevent the disease related complications and deformities. Patients developing deformities during and after treatment point out the availability/access to proper prevention services. Regular periodic examinations for nerve function impairment and complications in leprosy during and after MDT is essential as leprosy patients can develop disability even during treatment. The social stigma is still prevalent and involvement of family and communities is needed to eliminate it. Special emphasis on physiotherapy is needed along with the initiation of the treatment. It would be profitable to focus on enhancing the

rehabilitation services at peripheral centres during and after treatment.

Acknowledgements

The authors are grateful to Dr. Anantha Reddy and staff of Shivananda Rehabilitation Home for sharing the data. I also thank all the patients who participated in the study and cooperated for the study.

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How to cite this article : Anjum V, Swarupa MSK and Neeluri R (2017). Disability Status of the Leprosy Patients Enrolled in a Tertiary Health Centre in Metropolitan City. *Indian J Lepr*. **89** : 15-22.