



Original Article:

Determinants and Associated Disability of Leprosy Patients Attending GMLF, Sevagram

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Abstract: Background: Leprosy, as an oldest disease known to a man and already eliminated from India in 2005, still poses a public health problem with steady new case detection rate. Method: The present study was carried out in Gandhi memorial leprosy foundation, Wardha, with the aim to find out proportion of multibacillary leprosy cases and various grading of disability and factors associated with it in this part of country. All the successive new OPD patients were included in study and examined for type of leprosy and grade of disability if present. Analysis done by Descriptive statistics. Result: 66 % had multibacillary type of leprosy and 44 % the disability. Higher age group, females, illiterate and less educated, unskilled and low income group were mostly affected. Conclusion: high proportion of multibacillary cases and disabilities reflects the need for active thrust to identify new cases.

Key Words: Outpatient; Multibacillary; Disability; Females; Stigma

Introduction:

Leprosy is the oldest disease known to man. The earliest written records describing true leprosy came from India around the period 600 BC. *Mycobacterium leprae*, the causative organism was identified first by the Norwegian, Dr Amsauer Hansen, in 1873. (1) Though on 31st December 2005, India announced the elimination of leprosy, more than one lakh cases are detected every year and mostly one in ten are youths, indicating the active transmission of leprosy in India. (2) In 2012, of the 219, 075 new cases reported globally, 127, 295 were detected

in India itself. Among them, 10 per cent were children. In contrast to the sharp decline in leprosy prevalence, New Case Detection Rate (NCDR) has remained stable, with annual new case detection rate being 10.35/ lac population with marginal reduction of 1.24 % from 2010-12. (3,4) These counterintuitive findings indicate that achievement of the leprosy elimination goal should not be construed as though leprosy is no longer a public health problem.

Leprosy affects the peripheral nervous system and in the absence of timely treatment this will lead to irreversible neuropathy in a large proportion of cases. This in turn leads to secondary impairments, such as wounds caused by burns or pressure on the sole of the foot, contractures of fingers and toes and visual impairment. These impairments can finally lead to limitations in activities of daily living and/or restrictions in social participation. Among the new cases detected in India, approximately 3.78 and 3 per cent have grade 1 and 2 disability respectively, referring to the presence of visible (and often permanent) deformity. (4) It has been estimated that in 2015 there will be nearly 500,000 people living in India with grade 2 disability due to leprosy. (5) The main concern for leprosy has been linked with stigma that not only affect the individual but also impact on public health programme. (6,7) They may conceal the disease or deny the condition, resulting in delay in seeking treatment, increasing the chances of further progression to deformities. Compliance to treatment is also poor in some. Widespread implementation of Multidrug therapy had widely reduced the prevalence rate of leprosy from 57.6 /10,000 in 1981 to 0.68 cases per 10,000 populations in April 2012, (4) but it remains

a leading cause of preventable disability in India and poses a major public health challenge for the country. The WHO enhanced the global strategy for further reducing the disease burden due to leprosy (plan period 2011-15) under which the target was to reduce the number of new cases of leprosy with grade-2 disability (G2D) per 100000 population by at least 35% between the end of 2010 and the end of 2015 instead of leprosy prevalence.(8) In 1995-2010, G2D has decreased every 5 years by 12.7% in Brazil, 7.7% in China, 53.7% in India, and 35.9% in Thailand (endemic countries in the world at present).(5)

A low proportion of newly detected leprosy cases with grade 2 disability is an indicator of a successful control programme, but does not provide much information on actual health burden, both at the individual and population levels. For this we have to assess for grade 1 disability also for disability limitation and mitigation. Patients with multibacillary leprosy have more bacterial load, so more infectious and this is more likely to be responsible for disease burden.

The present study was carried out at Gandhi Memorial Leprosy Foundation (GMLF), Wardha. The first attempt to deal with leprosy as a public health problem was taken up in 1952 by the Gandhi Memorial Leprosy Foundation, an institution started under the Gandhi Memorial Trust. SET (Survey, Education, Treatment) programme, initiated by GMLF was a standard procedure for control of leprosy in the entire country and later, the WHO also endorsed the method, and it was adopted the world over. The aim of the present study was to know the socio-demographic profile of the leprosy patients, proportion of multibacillary leprosy and proportion of cases with different grading of disability and factors associated with it in this part of the country.

Methodology:

GMLF, Sevagram, Wardha unit (established in 1952) works in 27 villages in Wardha district with a population of 47,030; referral hospital (1965) runs an out-patient clinic six days a week; indoor wing and rehabilitation centre has 32 beds, and is used for training. All the hundred successive patients (New) attending the OPD at GMLF were included in the study from Jan 2012. The leprosy patients were interviewed face to face with structured questionnaire filled up after building the rapport and assuring the anonymity. Study variables were age, sex, social status according to modified Prasad classification (9) and occupation. Patient was examined for type of leprosy and grades of disability according to WHO criteria.(10) Descriptive statistical analysis was done in MS Excel.

Results:

Table 1 shows the socio-demographic profile of leprosy patients; 66 % had multibacillary type of leprosy and 34 % had paucibacillary leprosy, 64 % were male and 36 % females. Multibacillary leprosy was found in 70% and 71% of males of 40- 60 years and more than 60 years respectively and among 57% and 87.5 % of females of 40- 60 years and more than 60 years respectively. Among those with multibacillary leprosy, 78.5% males and 85.7 % females were illiterate. Multibacillary leprosy was seen in 70.3% unskilled male workers and 72 % unskilled female workers. Higher proportion of multibacillary leprosy was found in class 5 (83%) composite of both sexes followed by class 4 (80%).

Hand and feet disabilities were found in 44% of cases as shown in Table 2. Disabilities were found in 49.9 % of females, compared to 40.6% of males. Disability was present in 56% of illiterate and 75% primary educated patients. Higher education patients presented less often with disability. Of unskilled workers, 46.6% presented with disability while only 20% of skilled workers had disability, that too of grade 1. Among patients belonging to class 3, 70.4% had no disability while only 22.7% and 14.3% of class 3 and 5

respectively had no disability. Six percent patients had disability of eyes. None of the patients in young age group had disability of eyes. Almost equal number of females and males had eye disability (5.55% and 6.25%). Also patients educated secondary level and above and skilled workers had no disability of eyes. Of the patients belonging to class 5, 71.4% had grade 2 disabilities of eyes which is far more than other classes.

Table 1: Socio-demographic distribution as per type of Leprosy patients

Age	Male (64)		Total (64)	Female(36)		Total (36)
	Multibacillary (40)	Paucibacillary (24)		Multibacillary (26)	Paucibacillary (10)	
21-40	6 (37.5%)	10 (62.5%)	16	4 (66.7%)	2 (33.3%)	6
41-60	14 (70%)	6 (30%)	20	8 (57.1%)	6 (42.8%)	14
>61	20 (71.4%)	8 (28.6%)	28	14 (87.5%)	2(12.5%)	16
Education						
Illiterate	22 (78.5%)	6 (21.4%)	28	24 (85.7%)	4 (14.3%)	28
Primary	8 (100%)	0	8	0	0	0
Secondary	6 (37.5%)	10 (62.5%)	16	2 (100%)	0	2
Higher Secondary	4 (66.7%)	2 (33.3%)	6	0	4 (100%)	4
Graduate	0	6 (100%)	6	0	2 (100%)	2
Occupation						
Unskilled	38 (70.3%)	16 (29.6%)	54	26 (72.2%)	10 (27.8%)	36
Skilled	2 (20%)	8 (80%)	10	0	0	0
Income (in Rs)						
Class 3	26 (55.3%)	21 (44.7%)	47	16 (66.7%)	8 (33.3%)	24
Class 4	12 (85.7%)	2 (14.3%)	14	6 (75%)	2 (25%)	8
Class 5	2 (66.7%)	1 (33.3%)	3	4 (100%)	0	4

Table 2: Distribution of patient as per grade of disability of either hand and feet with socio demographic characteristics

Age/Grade	Hands & Feet (%)			Total
	0(56)	1(22)	2(22)	
21-40yrs	16(72.7%)	4 (18.2%)	2 (9.1%)	22
41-60yrs	24(70.6%)	6 (17.6%)	4(11.8%)	34
>60yrs	16 (36.4%)	12 (27.3%)	16(36.4%)	44
Sex				
Male	40(62.5%)	18 (28.1%)	8 (12.5%)	64
Female	16(44.4%)	4 (11.1%)	14 (38.88%)	36
Education				
Illiterate	26(43.3%)	16 (26.7%)	18 (30%)	60
Primary	2 (25%)	4 (50%)	2 (25%)	8
Secondary	10(71.4%)	2 (14.3%)	2(14.3%)	14
Higher Secondary	10 (100%)	0	0	10
Graduate	8 (100%)	0	0	8
Occupation				
Unskilled	48(53.3%)	20 (22.2%)	22(24.4%)	90
Skilled	8 (80%)	2 (20%)	0	10
Income				
Class 3	50(70.4%)	13 (18.3%)	08(11.3%)	71
Class 4	05(22.7%)	07 (31.8%)	10 (44.45%)	22
Class 5	01(14.3%)	02 (28.6%)	04(57.1%)	07

Discussion:

As WHO encourages integrating leprosy care into the general health service, leprosy patients are treated in the same outpatient department as those with any other disease, and our centre is also now working as a Primary Health Centre. As the prevalence of leprosy has decreased to elimination level in the community, it required more than one year to get

100 patients of leprosy. In the present study, proportion of multibacillary cases among new patients was 66% which is higher than India's average of 49% in 2012.(4) The probable reason may be that most of the leprosy patients diagnosed elsewhere in Wardha district are referred to this centre for further management and rehabilitation. Also lowered index of suspicion and delay in diagnosis may lead to increase in the proportion of multibacillary cases and increased incidence of disability as occurred in this present study. Also, owing to the stigma associated with the condition, people may conceal or deny their disease and delay seeking treatment, which may result in the worsening of the disease, increasing the risk of complications and of transmission of the disease in the community.(6,7)

Age/Grade	Eye (%)		
	0(94)	2(06)	Total
21-40yrs	22(100%)	0	22
41-60yrs	32(94.1%)	2(5.9%)	34
>60yrs	40(90.9%)	4(9.1%)	44
Sex			
Male	60(93.75%)	4 (6.25%)	64
Female	34(94.45%)	2 (5.55%)	36
Education			
Illiterate	56(93.3%)	4(6.7%)	60
Primary	6 (75%)	2(25%)	8
Secondary	14 (100%)	0	14
Higher Secondary	10 (100%)	0	10
Graduate	8 (100%)	0	8
Occupation			
Unskilled	94 (93.3%)	6(6.7%)	90
Skilled	10 (100%)	0	10
Income			
Class 3	70 (98.6%)	01(1.4%)	71
Class 4	21 (95.5%)	01 (4.5%)	22
Class 5	02(28.6%)	05(71.4%)	07

The proportion of females was 34%, which is similar to India's figure of 37%.(4) However no children below 15 years were found in this study. Most affected (44%) were above 60 years of age group. That means the disease is not active and spreading in community. The illiterate and primary educated (64%), unskilled workers (90%) and low income group were mostly affected by leprosy and suffered multibacillary type of leprosy as compared to others. The condition is favourable for spreading of leprosy in low socioeconomic group with overcrowding, lack of ventilation and having myths of leprosy.

Among the patients attending this centre, 22% and 6% had already progressed to grade 2 disabilities of either hand or feet and eyes respectively. It is far worse than the national figure of 3%.(4) It may be due to hospital based nature of the study. But another study states that a third of newly diagnosed patients have nerve damage and might develop disabilities, although the proportion varies according to several factors, including level of self-care.(11) Higher the age group, more the chances of developing grade 2 disability. As females are more stigmatized due to disease condition, they are detected at late stage when deformity has already progressed to grade 2; as depicted in Table 2 and 3, 44% and 61% females had no disability of hand, feet and eyes respectively compared to males (62 % and 84% respectively). A review of leprosy patients in South East Nigeria from 1988 to 1997 also found that the effects were greater in women

than men(12) and women complications and disabilities also tend to present late.(13)

Also the patients with higher age group, low educational status, and low social status present late in disease with grade 1 or grade 2 disabilities. Here also stigma plays a crucial role. Stigma enforces the inequalities that are found in the community with regards to gender, age and social class.(14) Most studies have shown that the stigma of leprosy is aggravated by the physical deformities associated with the disease.(15,16)

Grade 2 disability is considered as a key indicator for the successful control programme. It is a robust marker of the level of occurrence of disease in the community and operationally it is easier to recognize compared to the early signs of the disease. Aim of the control programme should not only be to get an insight of the disease burden and but also of the cost effectiveness of alleviating the disability; for that, it is necessary to detect grade 1 disability by early diagnosis and further prevent grade 2 disability which is more difficult to treat and rehabilitate. Most primary impairments are caused by reaction and neuritis which can occur before, during or even after MDT is completed. This can be easily avoided or treated at primary or secondary level health services, whereas, grade 2 disability requires reconstruction surgeries. The deformities and associated social stigma not only cause physical impairments but also activity limitation, and participation restriction for which Rao and colleagues had developed the new indicator, disability adjusted working life years (DAWLY) for measuring the burden of leprosy.(17)

Therefore, programmes that prevent disabilities or identify patients most at risk of developing them can reduce the effects of stigma. Education and media campaigns help to correct false beliefs and raise awareness of new advances. They include information about leprosy and its treatment, context-specific media messages addressing misconceptions and traditional beliefs about leprosy, positive images of leprosy and testimonies of people successfully cured of leprosy. Also some proven strategies like Stigma Elimination Program (STEP) used in Nepal (18) and social marketing used in Sri Lanka can be helpful in reducing the burden due to physical, mental and socioeconomic consequences of leprosy on persons affected and their families.(19)

Conclusion:

Sixty four percent of new patients had multibacillary leprosy and 44% had developed deformity. Higher age group, illiterate, unskilled workers and low income group mostly suffered from multibacillary leprosy and had higher incidence of disability than other groups. Half of females had already progressed to disability at the time of diagnosis of disease. This reflects the failure of the system for early diagnosis of disease, that in turn might be due to prevalent stigma in society that varies according to age, gender, education and social status of individual.

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