

## Trend in decline in leprosy disabilities of a LEPRA project in Malkangiri district, Odisha, India

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This is a retrospective analysis of the changes in 646 disabilities occurred amongst 3979 cases registered during 19 years from 1992 to 2010 in Malkangiri district. This amounted to 16.2% of cases with disability segregated to 310 (48%) Grade 1 and 336 (52%) Grade 2. In this project, managed by LEPRA India, POD care was in practice from the year 1992 and records were updated regularly. An analysis of the annual records showed that the net year-end balance increased up to the year 2001 followed by gradual decline. Within this period the total cases with disabilities declined by about 369 (57%) due to death by aging 204 (55%), migration from the area 77 (21%) and reversing to normal 88 (24%) in cases. Deletion due to recovery to normal especially with sensory impairment is fairly good with or without steroid. Disability percentage in new cases declined steadily especially Grade 2 from 30 % to 1%, initial high rate attributed mostly to backlog cases. In later years the rate is erratic high amongst low number of new cases. Absolute number indicates the situation better. Such study helps to roughly extrapolate the existing disability load in a particular area and assists in planning for care and prevention.

**Key words :** Deletion, total disability, inter-conversion, impairment

### Introduction

Leprosy mostly affects skin and peripheral nerves. If not treated early it damages the peripheral trunk nerves which results in disabilities. Most of them are permanent and lifelong problems even if the active disease heals with or without treatment. Hence in leprosy a state of cure and the continuing problems are different and it is rightly said that nerve damage and its consequences set leprosy apart from other diseases (Smith and Parkhe 1986).

Though introduction of MDT has reduced the incidence of disability drastically, the estimated total disability load in the world is estimated to be about 3 million (WHO 2009). Such a blanket statement on global burden is of limited practical use unless the cumulative numbers in control units are found out. This needs a shift of focus from Grade 2 disability in new cases to total disabilities in an area. We agree with the views that no attempt has been made to find out the

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total baseline load in any area and it continues to be a challenge (Madhavan et al 2007). Moreover such load is also likely to fluctuate in terms of total number and individual grades of 0 to 2 as classified for field operation (WHO 1988). So the problem of total disability remains less addressed an issue in terms of both the trend and length of service need. How long the disability related problem continues with the cohort of affected persons and at what rate it declines with time are events of considerable interest. The objective of this paper is to analyze the annual reports chronologically, events related to cumulative disabilities along with the influencing factors and find out the changing trend over a period of 19 years from 1992 to 2010.

### Materials and Methods

As a support to the MDT programme in Malkangiri district, a project by LEPRO India was started in 1992, in which 3979 leprosy cases were treated with MDT by the year 2010. There were 646 cases with disability which included 310 Grade 1 and 336 Grade 2. Field staff constituted 8 paramedical workers (PMWs), 2 non medical supervisors (NMS) and 2 physio-technicians working under the supervision of a project officer. It was the routine in the project to assess all the new cases for disability immediately after registration and the POD cards and POD registry was prepared and maintained in the project. Thus all the cases detected from 1992 to 2010 constitute the subjects of this study. They received the POD/POWD related services as per standard NLEP guidelines (Srinivasan 1993), which included self care, physiotherapy, wax therapy, electric nerve stimulation, steroid medication and reconstructive surgery. There was provision for admission in indoor wards for nerve function impairment (NFI), severe reaction, complicated ulcers and reconstructive surgery. The schedule of periodical follow ups was at an interval of 15 days

for cases on steroid, quarterly for disability cases and yearly surveillance for Grade 0 cases. Such schedule was followed up to 2010 with minor modification of follow up intervals. NFI cases reporting within 6 months of onset were treated with steroid and physiotherapy as per the protocol of the project. Protective footwear including those with orthosis were prepared in the LEPRO project's shoe manufacture units and were provided by the project field staff until 2007, thereafter through the POD activities conducted in primary health centers. The cards were updated after follow up visits, noting the events of death, leaving the control area (LCA) and inter-conversion in disability grade. From the information available it was possible to compile the year wise new disabilities and cumulative disability (old + new = total burden – deletion = balance, that was carried over to the following year as old). All causes for deletions in a particular year were sorted out and grouped into three categories: death, LCA and inter-conversion between the grades including reversion to normal. The pattern of deletion for each grade, causes of deletions and inter-conversion in grades were compiled annually from the quarterly reports and shown in result. Along with this the annual new cases detection and rate of disability (percentage in new cases) for each grade are also provided. As per the national programme these were routinely collected for the MIS report. To project the future trend the average of addition and average of deletion were found out from the year cumulative case started declining. This started from the year 2002 for Grade 1. It is presumed that even in the higher side disability would decline by that deletion minus addition. The total period required is calculated by dividing the balance by the difference of deletion minus addition. Similar calculation was also made for Grade 2.

## Results

The total cases registered in the district during the period were 3979 with disability in 646 (16.2%) of cases. As shown in table 1, the Grade 1 and Grade 2 disabilities respectively constituted 310 (7.8%) and 336 (8.4%). The absolute number of cases with disability including the balance after deletion increased year by year and both grades peaked in 2001. This was followed by decline in

the balance due to increased deletion compared to addition of new disability. By the end of 2010 the number of cases reduced by 224 (72%) Grade 1 and 145 (43%) Grade 2 respectively (Table 1). Both grades taken together total deletion due to various causes is 369 (57%) as shown in table 3. Deletion was maximum with 204 (55%) deaths by aging and other disease. The age and gender distribution of cases of death is given in table 4.

**Table 1 : Shows detail trend of changes in disability**

Year	Total New leprosy-cases	Year wise updated disability Gr. 1						Year wise updated disability Gr. 2					
		Old	New	Gr. I in new cases	Total	Dele- tion	Cumm Balance	Old	New	Gr. II Rate in new cases	Total	Dele- tion	Cumm Balance
1992	82	0	9	11	9	0	9	0	25	30	25	0	25
1993	574	9	77	13	86	4	82	25	77	13	102	5	97
1994	725	82	55	8	137	13	124	97	57	8	154	5	149
1995	327	124	17	5	141	13	128	149	32	10	181	7	174
1996	277	128	24	9	152	18	134	174	27	10	201	7	194
1997	296	134	26	9	160	15	145	194	23	8	217	8	209
1998	331	145	19	6	164	13	151	209	27	8	236	13	223
1999	229	151	18	8	169	14	155	223	13	6	236	10	226
2000	351	155	25	7	180	19	161	226	18	5	244	9	235
2001	226	161	9	4	170	8	162	235	7	3	242	6	236
2002	163	162	3	3	165	14	151	236	4	2	240	4	236
2003	87	151	5	6	156	13	143	236	1	1	237	8	229
2004	70	143	2	3	145	9	136	229	1	1	230	6	224
2005	33	136	1	3	137	8	129	224	1	3	225	6	219
2006	28	129	1	4	130	17	113	219	1	4	220	12	208
2007	53	113	5	9	118	19	99	208	5	9	213	14	199
2008	36	99	7	19	106	7	99	199	2	5	201	8	193
2009	56	99	4	7	103	11	92	193	7	12	200	10	190
2010	35	92	3	9	95	9	86	190	8	23	198	7	191
Total	3979	86	310	-	-	224	86	191	336	-	-	145	191
Change in each grade		86	-	-	-	72%	28%	191	-	-	-	43%	57%
Change in total disability		-	-	-	-	35%	13%	-	-	-	-	22%	30%

**Table 2 : Showing the total inter-conversion in between grades in 19 years**

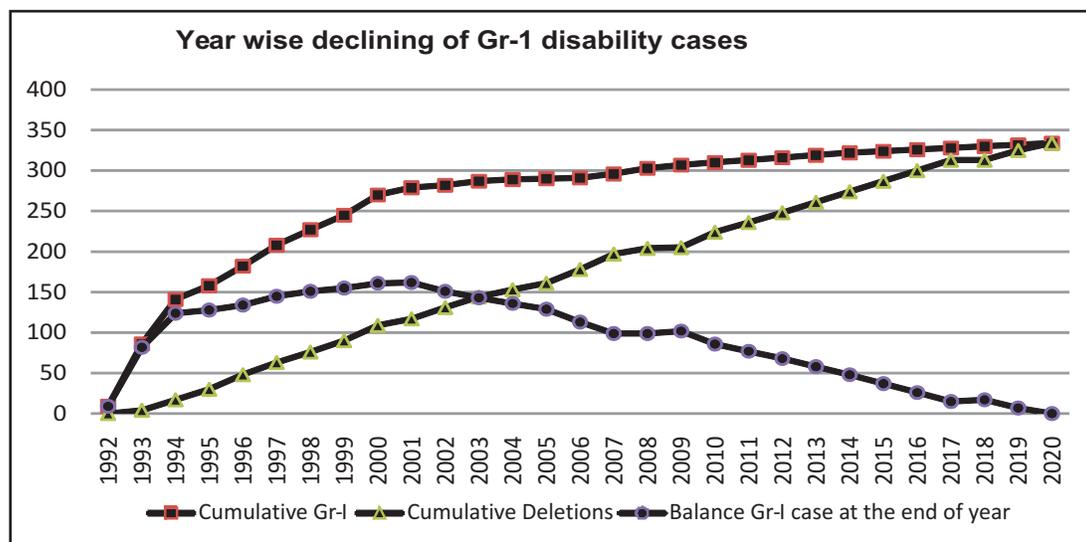
Conversion	Gr.0 to Gr. 1	Gr.0 to Gr.2	Gr.1 to Gr-2	Gr.1 to Gr.0	Gr-2 to Gr-0	Total
No	6	4	12	83	5	110
%	5	4	11	75	5	100

**Table 3 : Total deletions of cases due to various causes**

Grade	Died (%)	Recovery (%)	LCA (%)	Total
Gr-1	94(42)	83 (37)	47(21)	224
Gr-2	110(76)	5 (3)	30 (21)	145
Total	204 (55)	88 (24)	77 (21)	369

**Table 4 : Age and sex wise segregation disabled cases who died**

Age in yrs.	<30		31-40		41-50		51-60		61-70		>70		Total
	M	F	M	F	M	F	M	F	M	F	M	F	
Grade-1	1	0	8	3	15	4	28	7	17	5	6	0	94
Grade-2	0	1	5	8	16	11	22	14	11	11	6	5	110
Total	1	1	13	11	31	15	50	21	28	16	12	5	204
Grand total (%)	2(1)		24 (12)		46 (22)		71(35)		44 (22)		17 (8)		204(100)

**Fig 1 : Year wise declining of Grade-1 disability cases**

The highest number of death was in the age range of 51-60 years. Inter-conversion in type of disability occurred in 110 (30%). These were,

0 to 1 in 6 (5 %) cases; 0 to 2 in 4 (4%); 1 to 2 in 12 (11%); 1 to 0 in 83 (75%) and 2 to 0 in 5 (5%) cases (Table 2). Thus deletion due to recovery to

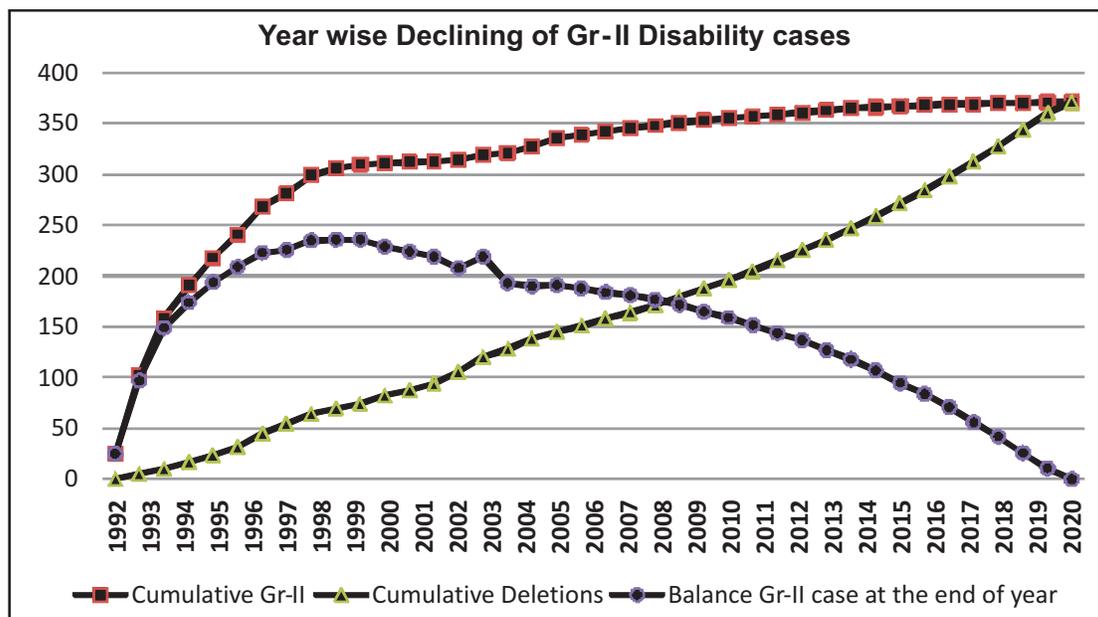


Fig 2 : Year wise declining of Grade-2 disability cases

normal (disability 0) was found in 88 (24%) cases. The third group for deletion was 77 (21%) cases declared LCA. The LCA group is lost to follow up and a common observation in some field projects. Both Grade 1 and Grade 2 cases deleted at the end of 2010 were 224 (35%) and 145 (22%) respectively with a total 57%. The year wise decline in both the grades is depicted in Figure-1 and 2. The disability rate in new cases seems declining with passing years but such trend is found distorted (erratic high and low rates in individual years) as the new case detection declines, in both the disability grades. In low new case detection stage absolute numbers are preferable as rate does not reflect the real situation.

### Discussion

The preoccupation of the National Leprosy Eradication Programme (NLEP) for a long time had been case detection for MDT and during the

period disability related problems received limited attention (Madhavan et al 2007). Though MDT has prevented Grade 2 disability in considerable number of cases this is not well appreciated by the affected persons and community who associate leprosy mostly with existing disabilities (Thorat 2009). Disability Prevention and Medical Rehabilitation (DPMR) launched in 2007 has ushered great hope to address the problems of disability (DGHS 2007). This is further strengthened by the WHO revised strategy integrating disability prevention into leprosy control as a quality component (WHO 2006). DPMR programme is expected to address not only disability in new cases but the problem of total disability. But the main focus still continues to be around proportion of disability Grade 2 in new cases, which represents only a limited fraction of the problem. It is probably the time to comprehensively plan for total disability care. A major initiative for enhanced coverage of POD

was Consensus Development Conference (CDC) held in 2006. The feedback collected on its recommendations from a number of countries emphasized on urgent need of increased coverage and access to POD services and the need to update the total disability burden in a community (Cross 2010). There are also suggestions to reassess the number of persons living with disability in the implementation units at national level (Joshi 2009). In this paper it was attempted for a retrospective cohort analysis of all cases of disabilities in a project covering Malkangiri district, implemented by LEPR India. The objective was to find out the changing profile of total leprosy related disability during 1992 to 2010.

With a strong conviction that MDT without addressing the consequences of nerve damage is incomplete, LEPR India incorporated POD services in its projects since 1992. Out of 3979 leprosy cases treated 646 (16.2%) developed disabilities which included 7.8% Grade 1 and 8.2% Grade 2. the number in either grade fluctuating annually with addition, deletion and inter-conversion. An attempt was made to show such changes in the total load in the project area. Emphasis on such evolutionary process in affected individuals and population has been given in other studies with different socio-economic implications (Smith 1992). Analysis reflecting the change in total disability is limited in the literature and some studies having some relevance are referred here. Review of observations in Thailand and Nepal summarizes that about one third of MB and 10% of PB cases may be in need of life-long POD activities mostly in the form of self care (Brakel 2000). The important observation in the present study is the drastic reduction in the disability burden in the affected community with passing years. Both the grades taken together, there is a decline to the tune of 57% with proportion of reduction higher (72%)

among Grade 1 while much lower (43 %) among Grade2 cases (Table 1). From the table it is evident that total disability cases and cumulative total balance after deletion increased up to around the year 2001. In subsequent years new disability declined and deletions increased, leading to decrease of balance cases.

Other observation in the present exercise is that, out of 369 deleted cases, a total of 204 (56%) deletion is due to death by aging and other diseases. The age segregation of disabled cases died is indicated in table 4. A total of 71 (35%) deaths were in the age group ranging 51-60 years. The life expectancy in the tribal population of the area is around 50 years (Table 4). It is encouraging to find 88 (24%) cases reversing the normal among total 369 deleted (Table 3), and 80% of 110 cases showing inter-conversion (Table 2). Causes of such reversion to normal are due to self care, treatment by steroids, physiotherapy and spontaneous healing. Recovery has been found in as high as 88% of patients (Saunderson et al 2000) in the acute neuropathy group in the prospective cohort of ALERT MDT Field Evaluation Study. Still encouraging finding in their study is the recovery in a fourth to one third of affected nerves where the damage was long standing and was apparently irreversible. The recovery in such long cases is thought to be due to axonal regeneration. Their study also identified nerve impairment at diagnosis as a risk factor and opined that more severe neuropathies are less likely to have full recovery. Croft et al (2000) reviewed a large number of publications on response of NFI to steroid. This was in connection with publishing their prospective cohort study on treatment of acute NFI cases in Bangladesh. The recovery rate varied widely in the reviewed studies. In their own study 68% of sensory nerves and 67% of motor nerves showed improvement due to treatment with steroid at 12 months. Interestingly about one third of patients matching

to the study group but not randomly selected and 'unjustly untreated' also showed spontaneous improvement in sensory function in 62% and motor function in 33% of cases. This makes the role of prednisolone a bit ambiguous. Two groups of patients with mild sensory impairment (detected by monofilament but normal when tested with ball-pen) showed spontaneous recovery in 75% of cases in placebo group in trial for the efficacy of 12 week prednisolone (Brakel et al 2003). Recovery of particularly sensory impairment is considerably frequent than it is thought both with and without steroid. Seventy one (21%) cases in our study were lost to follow up due to LCA which is discouraging. Nothing could be done to check such poverty driven distress migration. Following training in self care as high as 80% patients with disability were found to be practicing regular self care as found in the follow-up (Madhavan et al 2007). It is presumed that many of the migrated persons of our study area might be on self care with critical cases availing some service in the workplace. Such issues deserve further study.

The programme's interest is to see a decline trend followed by disability free area at some point of time. From the average trend of new case detection and deletion in 10 years preceding 2010 and life span of the person in the area, a presumption on need can be made. As the trends are extended in the graphs, for Grade 1 and Grade 2 cases are likely to continue up to 2020 and 2030 respectively. It is not a module and could not be calculated by any tool if exists.

### Conclusion

Total disability rate among 3979 cases was 16.2% with Grade 1 and Grade 2 rates 7.8 and 8.2%. In a period of 19 years the total disability load declined by 57%. Decline was faster in Grade 1 cases. Death due to age and other disease was main cause followed by LCA and recovery.

Spontaneous recovery is common in Grade 1 cases. This type of study helps to roughly extrapolate the existing disability load in a particular area and assists in planning for care and prevention. Like updating cases during initial years of MDT, such exercise is helpful in roughly estimating total disability load in an area.

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