

## Training and Motivation of Grass-Root Level Workers in Leprosy are Critical to Accelerate Reaching Zero Leprosy Goals in India

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Grass root workers are critical in the effectiveness of National Leprosy Eradication Programme (NLEP). Personal interview surveys assessed their knowledge, attitudes, and perspectives in zero leprosy goals in the National Capital Territory (NCT) of Delhi. Representative random samples of 81 medical officers (MOs), 77 allied health personnel and 124 ASHA workers were interviewed. One-third of MOs had no prior leprosy experience. They felt the delay in reporting was due to ignorance, misconceptions regarding leprosy and its treatment and stigma. They agreed that the contact examination was important but inadequately done. Only half the centres had an adequate supply of MDT and Prednisolone. Half of allied health personnel did not know the cardinal signs of leprosy, nearly one third did not know how to prevent stigma, disabilities, or delayed reporting. They stated that better training and supervision are essential to motivate them in case detection, contact follow-up and counselling. Focused intensive education and motivation are needed for the grass root level workers to be more efficient and committed to detect early cases of leprosy and counsel the public to overcome stigma encouraging early reporting and better adherence to MDT. Most grass root workers were enthusiastic and hopeful of eradicating leprosy if given better training and supervision.

**Key Words:** India, Grass Root Workers Perceptions' Training, Motivation, Leprosy

### Introduction

India achieved elimination of leprosy as a public health problem (prevalence rate [PR] <one case/10,000 population) at the national level on January 1, 2006 (<http://dghs.gov.in> 2021). This was a major achievement for India through the National Leprosy Eradication Programme (NLEP), which is currently involved in reaching the zero leprosy goals set by the WHO (Govt. of India 2019, WHO 2021, White 2020). This is going to be a "Mission impossible" (Desikan 2017, Steinmann et al 2020, Scollard 2019) unless drastic changes

are made in the current strategies of the NLEP as enunciated in the Delphi study (Baghotia & Rao 2021).

One of the major strengths of the NLEP is the massive force of field-level leprosy workers, which will include the medical officers operating the primary health centres and the ancillary staff such as the auxiliary nurse midwives (ANM). Also the more recently inducted accredited social health activists (ASHA) workers who have a much closer relationships with the communities, wherein the problem lies are asset to the national

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leprosy eradication programme (Correia et al 2019, van't Noordende et al 2019).

Multi-drug therapy (MDT) has been a great boon and game-changer in the battle against leprosy (Smith et al 2017), but ignorance, apathy, misconceptions and a high level of leprosy stigma seems to obstruct early detection, early reporting and prompt treatment with MDT (Rao 2015). There is a general tendency to delay reporting at the leprosy centres till disabilities occur and thus many of the reported cases are multibacillary with significant disabilities (Rao & Suneetha 2018). Further, the patients tend to be predominantly men with low rates of women and children (Raju et al 2008). This trend must be attacked and changed, which is possible only by the field level leprosy workers such as the medical officers, auxiliary nurse-midwives (ANM) and ASHA (accredited social health activist) workers. They are the lynch pins for the success of NLEP in eradicating leprosy and making the “mission impossible” to “mission accomplished” (Lar et al 2023). However, there is a great need to train these grass-root level workers not just on leprosy and its treatment but to help in early detection, educate and dispel myths and misconceptions of leprosy and encourage early reporting to health centres and take regular treatment. Studies done elsewhere (Awofeso et al 2008) have shown that appropriate training can result in efficient workforce (Lar et al 2023) reported increase in early case detections of skin NTDs (Bansal et al 2021) reported the great contribution of ASHA workers in a mental health program after training in improving community relations and reducing stigma. As part of a doctoral thesis (Baghotia 2022) on challenges and gaps in eradicating leprosy, a survey was therefore undertaken to assess the perspectives of medical officers, ANM and other paramedical personnel and ASHA workers on meeting the challenges posed by disabilities and stigma and on the prospects of India reaching zero leprosy goals. Delhi being

an urban area, with interstate and inter district migration, five districts were randomly selected. These districts are East, Shahdara, Northwest, West and South Districts. Shahdara is among high endemic districts. As on March 2020, Delhi had PR of 0.41/10000 population and NCDR of 3.95/100000 population. The selected districts had NCDR of East=2.54; Shahdara=19.76; Northeast= 6.04; West =2.26 and south =2.19 per 100,000 population. Delhi is conducting active case detection as per National guidelines. The district with high endemicity and high disability grade II are priority district for leprosy elimination campaigns.

The study was carried out in the National Capital Territory (NCT) of Delhi, India. Major findings are presented, discussed and suitable recommendations made. The entire research proposal including collection of primary data and other interviews was approved by the MLCU Research and Ethics Committee in August 2020.

### **Material and Methods**

The setting for the studies was the National Capital Territory (NCT) of Delhi, India, and the surveys were carried out during 2020-22. Multi-stage, representative (stratified) random cluster samples of individuals from five out of the eleven districts of Delhi were chosen to reasonably represent the entire state. Currently 305 Doctors, 342 ANMs and 6223 ASHAs are involved under NLEP. Delhi has 95% area covered under Local bodies. Only 5% area can be considered rural area. Interviews were conducted with service providers (medical officers, paramedical staff and ASHAs) with separate pretested semi-structured questionnaires. All gave full cooperation and participated in the interviews. There was no non-response.

The medical officers of the primary health centres, the ANMs and the ASHA workers in these selected districts were chosen and personally interviewed using a special research proforma after obtaining

their informed consent and their cooperation assured. Data were entered onto Microsoft excel sheets analyzed using SPSS computer software.

## Results

### 1. Survey of Medical Officers:

A total of 81 MOs were studied, 36 men and 45 women. Fifty-nine (59) were MBBS, 5 had PG diploma and 17 had PG degree. Fifty (50) were MO, 22 were Senior MO, 3 were CMO, 3 Senior residents and 3 were Specialists. Nearly 30% (22 doctors) had no prior leprosy experience, 19 had 1-5 years' experience and the remaining 40 had more than 5 years of working in leprosy. Forty said they have hardly seen any leprosy patients in a year, and one doctor claims to have seen nearly 150 cases.

Most of the MOs stated that they have seen only a small number of cases in reaction, or with high BI, Grade 2 disabilities, nerve thickening and mostly have dealt with hypo pigmented anesthetic patches. The MOs felt the delay in reporting was due to lack of awareness and stigma. They further stated that the delay was avoidable and was probably responsible for continued transmission of the disease. MDT for both adults and children was available for only 40% of the time, Prednisolone for about 42% and other drugs for only 8%. Only 45% of family contacts could be examined and hardly any follow-up done. Only half the doctors felt the contact examination was important. Nearly 80% of doctors, both men and women, felt that the present case detection was effective, but

**Table 1 : Suggestions given by medical officers to stop transmission of leprosy.**

Suggestions to Stop Transmission of Leprosy	Men		Women		All	
	No.	%	No.	%	No.	%
Community Awareness	5	13.9	4	8.9	9	11.1
Adequate awareness and Early detection	7	19.4	7	15.6	14	17.3
Early detection/diagnosis and treatment	16	44.4	26	57.8	42	51.9
I don't know	8	22.2	8	17.8	16	19.8
Total	36	100.0	45	100.0	81	100.0

**Table 2 : Suggestions given by medical officers on how to prevent disability.**

How to Prevent Disability	Men		Women		All	
	No.	%	No.	%	No.	%
Adequate awareness and early detection	10	27.8	11	24.4	21	25.9
Early detection/diagnosis and treatment	14	38.9	23	51.1	37	45.7
I don't know	12	33.3	11	24.4	23	28.4
Total	36	100.0	45	100.0	81	100.0

could not explain further in terms of follow-up of contacts encouraging more women and children to attend PHCs. The suggestions given by the MO for stopping transmission of leprosy are presented in Table 1.

Most replies generally steer to more education but no specific suggestions on how the MOs can help. Suggestions given by medical officers for preventing disability are shown in Table 2.

Again, the replies are very superficial and general and not specific to follow up. About 20% of men and 7% of women doctors felt there was no leprosy stigma. The findings are not realistic and based on facts. More than 40% mention they have no suggestions to reduce stigma. Suggestions given by medical officers to achieve

zero case of leprosy in Delhi are shown in Table 3.

It is disappointing that over 70% of doctors who participated in the survey could not give cogent suggestions and simply attribute to need for more IEC.

#### 2. **Survey of ANM and other para-medicals:**

A total of 77 persons belonging to ANM and other para-medicals were studied. Of these, 55 were ANMs, 14 were nurses/health visitors, 2 physiotherapists, 2 NMS, 2 PMW, 1 lab technician and 1 pharmacist. Eleven were men and remaining 66 women. Their ages ranged from 23 to 57 years, with a mean (SD) of 40.7 (10.1) years. A vast majority, 55 (71%) had 10 years or more experience in public health work. Only 30 (39%) had some experience in leprosy work.

**Table 3 : Suggestions to achieve zero case of leprosy.**

Suggestions to Achieve Zero case of Leprosy	Men		Women		All	
	No.	%	No.	%	No.	%
More IEC in Hospitals and Fields	4	11.1	5	11.1	9	11.1
More trainings to healthcare workers	3	8.3	6	13.3	9	11.1
Lab diagnostic facility	0	0.0	2	4.4	2	2.5
No comments	29	80.6	32	71.1	61	75.3
Total	36	100.0	45	100.0	81	100.0

**Table 4 : Knowledge of ANM and other paramedical personnel regarding cardinal signs of leprosy.**

Symptoms	No		Yes		Total	
	No.	%	No.	%	No.	%
Anesthetic Patch	12	25.5	17	56.7	29	37.7
Anesthetic Patch + thickened nerve related to muscle weakness	4	8.5	3	10.0	7	9.1
Absorption of body parts	2	4.3	0	0.0	2	2.6
White Patch	4	8.5	3	10.0	7	9.1
Brown patch	6	12.8	0	0.0	6	7.8
Don't know	19	40.4	7	23.3	26	33.8
Total	47	100.0	30	100.0	77	100.0

Only 24 (31%) had on-the-job training in leprosy, and even among those who had no prior experience in leprosy, less than half had any training in leprosy. Only about half had some leprosy training in the past one year. In general, only about 20% said they have frequent training and nearly half said never or very occasionally. Knowledge on suspecting leprosy was quite poor; one-third said they didn't know, and less

than 50% could say it was anesthetic patch and/or muscle weakness. It is disappointing that even those with experience performed poorly.

Knowledge regarding cardinal signs and symptoms of leprosy is shown in Table 4.

To the question "What is the next course of action if you suspect a case of leprosy case in the OPD/Field?", 25% said they don't know, 50% felt they should have referred to a hospital and less

**Table 5 : Knowledge about prevention of transmission of leprosy.**

Prevent Transmission	NO		YES		All	
	No.	%	No.	%	No.	%
Education/Counselling	12	25.5	8	26.7	20	26.0
Early Detection/Vaccination	3	6.4	4	13.3	7	9.1
Treatment & Follow-up	13	27.7	16	53.3	29	37.7
Isolation/Mask	3	6.4	1	3.3	4	5.2
I don't know	16	34.0	1	3.3	17	22.1
Total	47	100.0	30	100.0	77	100.0

**Table 6 : Reducing stigma and discrimination due to leprosy.**

Reduce Stigma and Discrimination	NO		YES		All	
	No.	%	No.	%	No.	%
Effective IEC/Awareness	29	61.7	29	96.7	58	75.3
I don't know	18	38.3	1	3.3	19	24.7
Total	47	100.0	30	100.0	77	100.0

**Table 7 : ASHAs can help in leprosy contact tracing.**

How ASHAs can help	No.	Percent
Surveillance	23	18.6
Referral to Health Centre	20	16.1
Screening	18	14.5
Screening/Awareness	8	6.5
Help ANM	2	1.6
Don't know how	53	42.7
Total	124	100.0

**Table 8 : Difficulties faced by ASHA workers in leprosy work in the community.**

<b>Difficulties in leprosy work</b>	<b>No.</b>	<b>Percent</b>
Patients don't like to talk about their disease	28	22.6
Difficult to examine with their clothes on	18	14.5
Not allowing examination and hide the disease	17	13.7
Change in colour of skin/face	18	14.5
Stigma	14	11.3
Short term resident/migrants	5	4.0
No problem	24	19.4
<b>Total</b>	<b>124</b>	<b>100.0</b>

**Table 9 : Reasons given by ASHAs for leprosy stigma\*.**

<b>Reasons for Leprosy Stigma</b>	<b>No.</b>	<b>Percent</b>
Lack of awareness	7	8.6
Believe it is transmitted through touch and so this should be avoided	22	27.2
People refuse to tell/Fear of discrimination	8	9.9
Old orthodox thinking /Superstitions	33	40.7
I don't know	11	13.6
<b>Total</b>	<b>81</b>	<b>100.0</b>

\*Denominator 81 who felt that there was stigma.

than 20% said that MDT must be started. Their suggestions on how transmission of leprosy can be prevented are listed in Table 5.

Suggestions for decreasing stigma and discrimination due to leprosy are summarized in Table 6.

### **3. Survey of ASHA Workers:**

A total of 124 ASHA workers were surveyed. Their ages ranged from 21 to 65 years; 49 (39.5%) were aged 21-39 years; 55 (44.4%) were between 40-49 and the remaining 17 (13.7%) were 50 years or more. Thirty-six (29%) had studies less than high school, 30 (24.2%) high school and 58 (46.8%) beyond high school. Nearly 90% reside within their study area. Fifty-four (43.5%) worked earlier in public health, mostly in a dispensary or clinic. Eighty-three (67%) had some training in Leprosy.

One-third of ASHA workers never had any refresher course in leprosy, and about 30% were occasionally trained. Only 20% had regular orientation course in leprosy. They are mostly supervised by an ANM or public health nurse. Response to how they can help with leprosy contact tracing is given in Table 7.

About 40% did not know how they could help but were willing to assist. Most of the others felt they could help in screening, surveillance, IEC. Almost all knew that MDT is for leprosy, but 90% did not know the names of the drugs. About 30% said they were allowed to dispense MDT, but 12% dispensed only once and another 15% more than once.

The difficulties faced by leprosy workers in detecting and diagnosing leprosy in the

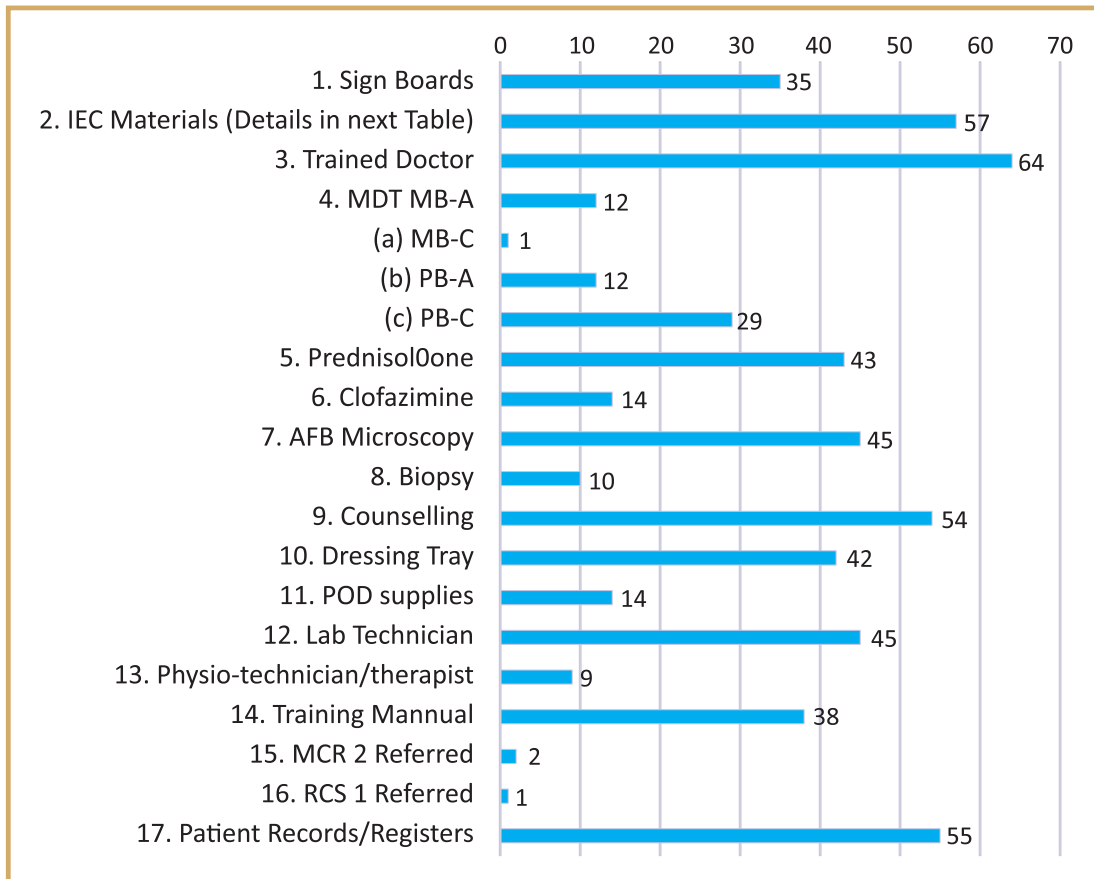


Fig. 1 : Availability of essentials in 70 institutions surveyed.

community are displayed in Table 8.

Nearly half the ASHA workers were eager to get help from NHM/NLEP for training and guidance in leprosy work. Only 81 (65%) ASHA workers felt there was a high degree of leprosy stigma mainly for reasons given in Table 9.

Nearly 70% felt that stigma can be removed through awareness about symptoms and mode of transmission and importance of taking drugs timely. Twenty (20) percent said they do not know. However, all were keen to help in removing stigma. Almost 90% of ASHA felt that it is possible to eradicate leprosy and bring down

the incidence to zero; 6% said it is not possible and the rest had no idea.

Seventy health care institutions were selected randomly to see the availability of healthcare facilities for leprosy patients using an observation checklist. The availability of essentials is given in Fig.1.

**Discussion**

The findings from the survey clearly show that all the three key grass-root level workers need additional training in leprosy. This need is quite apparent in the case of medical officers associated with the programme (Tables 1-3).

Further, the research also highlights the weak motivation of all these workers to intensively follow up the suspects and educate them on the importance of early reporting and full adherence of MDT which is very important for stopping the transmission (Table 3, 5).

While the medical officers and the ANM are professionally trained, they lack the critical knowledge and proper attitudes to pursue detection of hidden cases and contacts of all MB patients, especially women and children. The medical officers are in a unique position not just to detect and treat but educate and motivate the patients to bring all the contacts for early detection of possible disease before disability sets in. Likewise, the ANMs have the opportunity to educate and motivate all women to detect cases of leprosy early enough and start prompt treatment where necessary. These two grass-root professionals must be regularly trained, well supervised and motivated as well as appreciated. These grass root workers are like the critical nails that must be taken care of. Over 97% patients are managed by hospitals with facility of dermatologist. Currently 32/1447 (2.21%) cases on record are treated by dispensaries. There are no typical PHCs/CHCs in Delhi like rural areas in other states. The peripheral units are dispensaries. Therefore, no such field staff under these dispensaries is posted in Delhi. However, paramedical staff posted on Delhi are pharmacist, ANMs and Lab technicians. The leprosy workers are primarily posted in hospitals.

Incidence and prevalence are calculated at district level as denominator for incidence is per 100,000 and prevalence per 10,000 population. The secondary data for PR, NCDR and other indicators were taken for the year 2011 to 2020 to eliminate the effect of Covid 19. Due to lockdown in Covid, patients were not able to reach to healthcare institutions. There was 54.55% reduction among new cases from 1824 in

2019-20 to 829 during 2020-21. Major challenge was treatment compliance as patients from outside Delhi (migratory patients) had difficulty to collect MDT. To improve the treatment compliance, healthcare institutions were advised to issue MDT to patients registered for treatment even in other healthcare institutions. Our study shows that appropriate training and motivation is required for all category of workers involved in leprosy work for urban settings of Delhi, same may be the situation in other cities.

The newly appointed ASHA workers of the National Health Missions are potentially important members in the leprosy control programmes but need good training and supervision if they are to be effective. The findings of the survey show they are enthusiastic and keen to help if given proper training (Tables 7-9). They are the closest to the people and can help dispel myths and misconceptions of leprosy and counsel the public to overcome both self and enacted stigma, which seems to be the main stumbling block for successful leprosy eradication (Raju et al 2008).

The survey has pointed out the major lacunae in both the knowledge and attitudes of the grass-root level workers (Table 4). In an earlier study, the expert panel of leprosy specialists concluded that to reach eradication, the most practical advice was better manpower training monitoring and supervision. The methodologies for implementing must be formulated by NLEP providing adequate budgets, incentives, and follow-up (Baghotia & Rao 2021).

Since ancient days, Leprosy was treated more as a social or spiritual problem and less as a disease that is curable (Bhat et al 2021). Disability was considered inevitable, and a person diagnosed with leprosy written off as dead. Hence, the plethora of shameful laws and other civil practices of isolation, discrimination and torture were prevalent. Much progress was made over the past century to change this picture through



discoveries of dapson, rifampicin, MDT, steroids and other powerful anti-inflammatory drugs that have fully transformed leprosy into a manageable disease with practically no disfiguring disabilities (Smith et al 2017). Yet, the negative psychosocial dimension remains stubbornly unchanged (Raju et al 2008). Not just the aetiology but also the strong link between leprosy and deformity remains the last fort to be conquered. Notably, disability is a major factor in generating and perpetuating stigma and discrimination, and advances in the scientific understanding of nerve injury can make a major contribution to the reduction in stigma and discrimination as well. The findings from the present study show only superficial knowledge of the problem and a weak motivation to address the issue of preventing disability through early detection and prompt treatment.

Except training of trainers which is conducted at state level, all other trainings are conducted at district level. Chief district medical officer is controlling officer as well as Mission Director NHM at district level. Keeping in view the shortage of staff, training are conducted from 1 pm to 6 pm. Still, it is not always possible to train all the medical officers and other staff which remains a big challenge under NLEP. This deficiency must be overcome if we want to achieve the goals set by NLEP as per new national strategic plan (NSP 2023-2027) which is in harmony with global goals (WHO 2021).

The results from this research, have shown that even the most powerful medicines will be ineffective in the light of apathy, ignorance and gross negativity of the public who still maintain the former image of leprosy as punishment or evil-driven, and thus make every action the government has taken to cure and prevent leprosy, ineffective. We are at a critical stage of eradicating leprosy and the commitment

and alertness of staff are essential to succeed especially in early detections and full adherence of MDT. Without their full cooperation the NLEP cannot succeed. Clinical and epidemiological characteristics of leprosy patients in post-elimination era indicate the need for close monitoring of situation (Mahajan et al 2021) as delay in diagnosis (Marfatia et al 2020) will not only lead to poorer outcomes and disabilities but will also result in continued transmission.

Baring few charitable hospitals, leprosy is a disease handles by government healthcare institutions. Leprosy services are mainly provided by secondary and tertiary care hospitals in dermatology department. However, some dispensaries are also providing leprosy treatment services. In case, a patient is suspected of having leprosy, is sent for skin smear examination to nearest hospital for further management. Reconstructive and rehabilitative services are provided by ILEP (The Leprosy Mission Hospital, Damien Foundation India Trust, and Lepa Society). Few government hospitals are also doing reconstructive surgery. There is clear need to augment the resources and capacity of health systems.

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