

Part - II

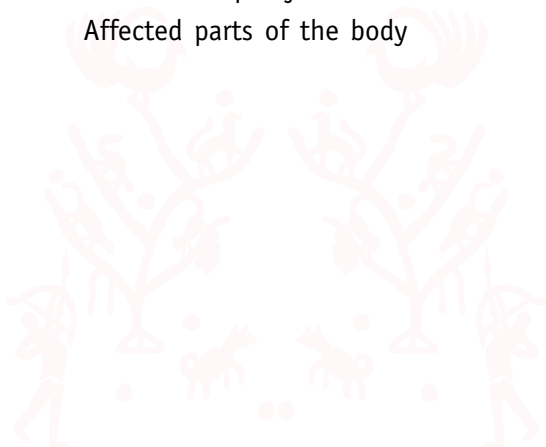
**Involvement of *Anganwadi*
Workers in MDT Service Delivery
in Joda Municipality,
Keonjhar District,
Orissa**

2002



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1. Introduction



The town of Joda is situated in northwest Orissa, in the mining belt bordering Jharkhand. It covers an area of 26.4 sq km and caters to a population of 39,632 (2002). Most people worked as mining labourers and industrial workers, having migrated from neighbouring areas and settled in the 31 slum colonies that form part of the Joda town.

The prevalence of leprosy and detection of new cases in Joda had been consistently high in the recent past (PR >20). Analysing current leprosy trends and considering the existing health infrastructure, it was jointly decided by the Government of Orissa (GoO) and the Danish Assistance to the National Leprosy Eradication Programme (DANLEP) to make an intervention involving the Integrated Child Development Scheme (ICDS) system in multi-drug treatment (MDT) service delivery, with particular emphasis on case-suspicion, MDT treatment, follow-up, reporting and maintenance of records.

2. Background



The leprosy situation

The prevalence rate of leprosy in Joda municipality was 19.7/10,000 pop. in March 2001 and had remained between 20 and 26 during the last five years. This rate was roughly three to four times higher than the PR at the district level. Similarly, the new case-detection rate (NCDR) varied between 28.4 and 25.9/10,000 pop. during the last five years. Among new cases, the proportion of disability was 1%, multi-bacillary (MB) was 22%, and child cases constituted 18% of the total.

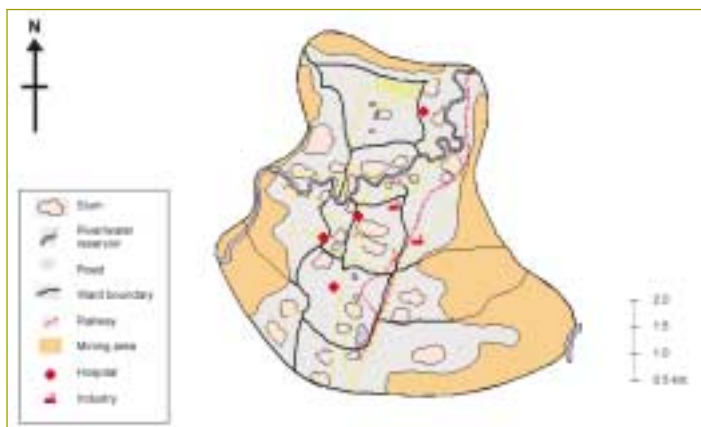
Community characteristics

Keonjhar district is home to a number of tribal peoples such as Bathudi, Bhuyan, Bhumij, Gond, Ho, Juang, Kharwar, Kisan, Kolha, Kora, Munda, Oraon, Santal, Saora, Sabar and Sounti. The Joda municipality is a mining area in the district. The population is characterized by low literacy, many languages and migratory labour patterns. The main languages include

Figure 1: Location of Keonjhar district in Orissa state



Figure 2: Joda municipality in Keonjhar district



different tribal languages and dialects, Hindi and Oriya. The total population was around 40,000 in 2001, of which Scheduled Tribes (ST) constituted 33% and Scheduled Castes (SC) 23%. The male-female ratio was 51:49.

Work pattern

Daily labourers worked in the iron ore mines, with the railway, in the forest or in other mining industries. Migration from the neighbouring states of Jharkhand, West Bengal and Chhattisgarh was increasing which posed a challenge for leprosy detection and follow-up, because workers were difficult to access during daytime.

Service-provision profile

The ICDS system had been functioning since 1997 with 31 *Anganwadi* Centres (AWCs) in 13 wards. There was one government hospital in Joda municipality to cater to the town's population. It had no field health staff. Two private hospitals, one run by the steel company, TISCO, and the Central Hospital, were not involved in preventive or curative leprosy-related health services for the general population but provided referral services for the employees of their respective companies. No general healthcare network existed to meet the growing needs of slum-dwellers.

Rationale for study and intervention

The *Anganwadi* Workers (AWWs) were the only grass-roots level workers in slums to provide a number of health services as there was no hospital-



Training of Anganwadi workers.

based field staff. Given the high PR for leprosy in the Joda municipal area, and given the successful involvement of AWWs in different health programmes, the GoO found it feasible to involve them in the delivery of MDT services and to evaluate the impact of this intervention.

The involvement of AWWs in three previous rounds of the modified leprosy elimination campaign (MLEC) had provided an excellent opportunity in terms of sensitisation and training. It was expected that the MDT service delivery with the involvement of ICDS system along with other partners, both inside and outside the health system, would help in the detection of a larger number of leprosy cases and ultimately contribute to the reduction of leprosy in the urban area.

Description of intervention and study design

A series of discussions were held with local programme managers and health and ICDS personnel for the involvement of AWWs in leprosy control. The AWWs were trained for one day about case-detection and treatment, maintenance of records, treatment records, report generation, and keeping accounts of stocks and stores. After the training they were supplied with separate registers to record suspect cases, treatment given and stock of medicines, monthly report forms and MDT drugs. The Paramedical Worker (PMW), Supervisor, Medical Officer (MO) and Child Development Project Officer (CDPO) supervised their work. At the monthly sector-level meeting AWWs submitted their monthly progress report (MPR) when their work was reviewed and they were supplied with medicines. The present study took place after six months of the intervention to evaluate its impact.

3. Methodology



Sampling

As the entire population of AWWs in Joda municipality was included in the study, sampling was not an issue for this part of the study. Sixteen persons diagnosed for leprosy between the times of intervention and data collection were interviewed. However, at the time of data collection, only 12 patients could be located. In addition, data were collected from all patients (N=35) under treatment from 1 June 2002 till end-December 2002.

Data collection

Different formats were developed to collect data after the intervention. Separate questionnaires were developed for AWWs and patients. They were pre-tested in a comparable setting and necessary changes were identified and implemented. The AWWs submitted the MPRs, which were collected and compiled by the PMW and ICDS supervisors, and monthly project reports were prepared for submission.

Data collection was done by Dr. U. N. Barik using the developed questionnaires and formats. He interviewed 30 AWWs and 12 patients. On the basis of the interviews, a master sheet was prepared.

Table 1 provides an overview of the study and the intervention processes.

Table 1: Time line for research and intervention process

SI.No.	Time	Study activity	Intervention activity
1	March 02	Preparation of proposal	Discussion with MO, CDPO SPMW and AWWs.
2	April 02	Development of formats and questionnaires	Assessment of prior knowledge and attitude concerning LEP and level of involvement of AWWs in leprosy work.
3	May 02	Development of proposal	Beginning of intervention; Training of AWWs.
4	June 02	Pre-testing of tools	Supply of medicines and registers.
5	July 02		Routine field visit by MO, CDPO, PMW, Supervisor; Collection of monthly report.
6	Nov 02	Training of Research Assistant	
7	Dec 02	Collection, data entry and initial analysis	
8	April 03	Data analysis and report-writing workshop; Presentation of findings to GoO.	

4. Results



Coverage, detection and treatment

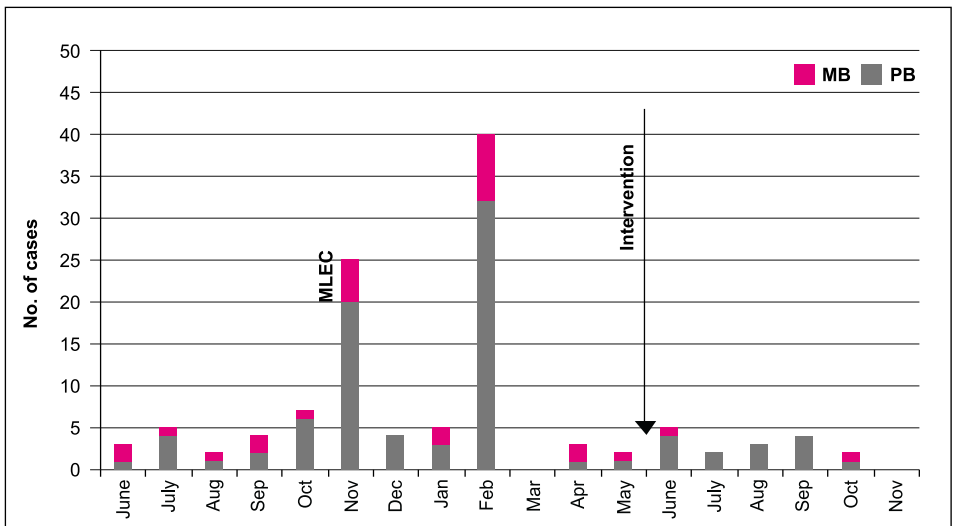
The PR has come down from 12.9 in the pre-intervention period to 7.7 in the post-intervention period (Table 2).

Table 2: PR (per 10,000 pop.) before and after intervention

	Before (Jan-May '02)	After (Jun-Nov '02)
PR	12.9	7.7

The high PR in the pre-intervention period was due to the detection of 38 cases in the leprosy elimination campaign (LEC) conducted during February 2002. Twenty-five leprosy cases were treated during the intervention period. Figure 3 shows the new cases detected before and after the intervention. However, the occurrence of MLEC and LEC

Figure 3: New case-detection, June 2001-November 2002



prior to the intervention made it difficult to assess its impact during the six months' framework of the study.

There was no substantial change in the profile of new cases detected in the post-intervention period (Jun-Nov. 02) compared to the pre-intervention period (Jan-May 02), as seen in Table 3.

Table 3: Case-detection profile

	Popln.	Case-detection			Female	Gr-II. deformity	Child	ST	SC	Vol.
		PB	MB	Total						
After interv.	39,089	13	4	17	7	0	5	7	3	1
Before interv.	38,691	31	11	42	17	1	6	21	4	0

The time-lag between the appearance of symptoms and the diagnosis of leprosy was slightly higher in the case of women than men (Table 4). It was premature to attempt to compare pre- and post-intervention time-gaps at the time of data collection, as insufficient time had passed after the intervention to allow for the possibility of delay. However, this question would be important to explore in a follow-up study. A decrease in the average delay would be expected due to frequent interaction between AWWs and the community, improved skills for case-detection and improved access to services in the post-intervention period.

Table 4: Delay in diagnosis of leprosy cases

Total amount of delay (in months)	373
Total number of patients	35
Average delay (in months)	10.7
Average delay for PB patients (in months)	10.6
Average delay for MB patients (in months)	10.9
Average delay, women (in months)	11.2
Average delay, men (in months)	10.7

Source: Patient cards of 35 patients under treatment, June-December 2002

Table 5: Availability of MDT after intervention at AWCs (June to Nov. 2002)

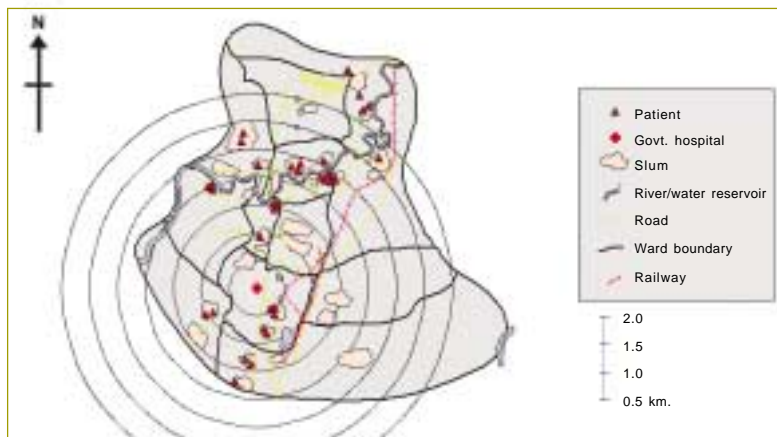
	AWCs	
Yes	26	84%
No	5	16%
TOTAL	31	100%

MDT was available in 26 of the 31 *Anganwadi* centres at the time of data collection (Table 5). In one AWC drugs could not be provided due to the death of the AWW. However, the AWW in the adjacent AWC was asked to provide services in her place. In another case, there was a shortage of drugs for a period of one month for one MB child. In the other three AWCs, where drugs were not available during data collection (24 & 25 December), AWWs had actually given the required medicines to all the patients and received new supplies on 27 December, a few days after data collection.

Access to services

Prior to the intervention, MDT was available at the Government Hospital located in the south of Joda municipality. Only one of the 35 patients registered in the treatment register during the period June to December 2002 lived within a distance of 500 metres from the MDT delivery point, i.e. the Government Hospital (Figure 4). The approximate average

Figure 4: Distance from MDT delivery point (Govt. Hospital) to patients' homes prior to the intervention

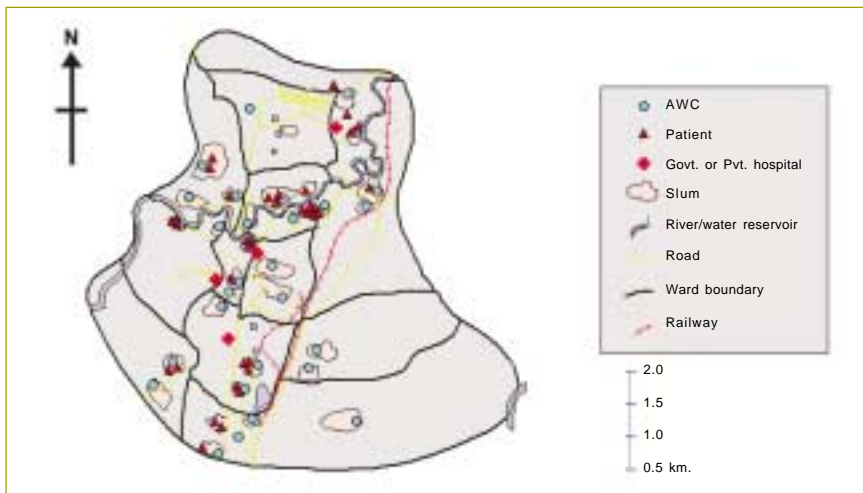


distance between residence and MDT delivery point was a little over 2 km (see Annexure 1 for an overview of data for the 35 patients).

However, this is the aerial distance, and the actual distance a patient may have to cover by road can easily be twice as long. Adding the waiting time at a government hospital, it could take several hours for the patient to obtain medicines, and this would compete with his/her other necessary domestic chores. Therefore, even if the distance at first glance may seem small prior to the intervention, it was believed that increased access – as well as embedding the MDT delivery in a context where the provider would have close contact with the household – would have a positive effect on the patients completing their treatment.

The intervention dramatically decreased the distance from the patients to service delivery points (AWCs), as is evident from Figure 5.

Figure 5: Distance from MDT delivery points (AWC) to patients after the intervention



Anganwadi workers and ICDS

Anganwadi workers were involved in the implementation of all activities of the ICDS programme, including pre-school activities, immunisation, referral of mother and child when necessary, home visits, mothers' meetings, and weighing of pregnant women and infants (0-6 yrs).

However, *Anganwadi* workers were also enrolled in various other health programmes. In Joda municipality AWWs were involved in the Revised National Tuberculosis Control Programme, Intensified Pulse Polio Immunization (IPPI), the vitamin A campaign and the Modified Leprosy Elimination Campaign (MLEC) as volunteers. As the health infrastructure for the delivery of MDT services in Joda was deficient, an initiative to integrate MDT delivery with the ICDS system was developed.



Training of *Anganwadi* workers.

This initiative involved a number of new tasks and hence a new role for AWWs. The new tasks included detection of suspected leprosy cases; referral for confirmation of diagnosis during routine home visit; keeping stock of MDT and delivery to new as well as previously diagnosed patients; maintenance of suspect-, treatment - and stock registers; provision of follow-up services; submission of MPR in the monthly sector meeting to the PMW; and provision of health education on leprosy with emphasis on the cause, early suspicion and prompt treatment with MDT.

Before their involvement in the intervention process, the AWWs received training in Oriya language about leprosy and MDT services, and their new role was defined. Table 6 provides an overview of the training input provided prior to the intervention.

Table 6: Training input to AWWs prior to intervention

Subject	Content
Early signs and symptoms	<ol style="list-style-type: none"> 1. Hypopigmented/coppery patch with definite loss of sensation (anaesthesia) 2. Oily and shiny skin 3. Dry skin 4. Loss of hair 5. Tingling and numbness 6. Nodule in ear
Causes of leprosy	<ol style="list-style-type: none"> 1. By germs (<i>Mycobacterium leprae</i>) 2. Not caused due to sin or curse, and not hereditary
Parts to be affected	Nerves and skin are commonly affected
Types of leprosy	<ol style="list-style-type: none"> 1. Single skin lesion (SSL) 2. Paucibacillary (PB) 3. Multibacillary (MB)
Treatment	Multi-drug therapy (MDT)
Curability	MDT can cure leprosy
Side-effects	<ol style="list-style-type: none"> 1. Red urine 2. Change of skin colour
Causes of referral	<ol style="list-style-type: none"> 1. Yellow colouration of eyes 2. Itching of the skin 3. Urticaria 4. Joint pain 5. Pain and tenderness of patches 6. Painful nodule in body.
Advice to the patient at the time of treatment	<ol style="list-style-type: none"> 1. To be regular in drug intake 2. Above-mentioned side-effects may occur 3. To make immediate contact if any adverse side-effects or complications occur
Health education to the community	<ol style="list-style-type: none"> 1. To be informed about early signs and symptoms of leprosy 2. To be informed of immediate reporting to AWW 3. To have regular discussions in monthly mothers' meeting, SHG meeting and also during home visits to increase community awareness about leprosy.

5. Leprosy Awareness after Training



Based on the input given during training, the AWWs (Total: 30) were interviewed six months after the training to assess the impact of the training as well as possible needs for further training. The following tables contain the responses given by the AWWs.

Signs and symptoms

Nineteen out of 30 respondents stated that an anaesthetic patch was a sign of leprosy, and 20 stated that hypopigmented coppery colour patches were signs of leprosy. Since one of the important signs of leprosy, i.e. oily and shiny skin, was missed out by the respondents, whereas late signs of leprosy like nodules and paralysis of eyelid were mentioned, it was felt necessary to give a second round of training to the AWWs to improve their ability to detect early signs of leprosy.

Table 7: Signs and symptoms of leprosy

Sign	Total (N=30)
Anaesthetic patch	19
White patch	8
Hypopigmented and coppery colour patch	20
Dry skin	3
Hairless patch	5
Inability to sweat	4
Tingling and numbness	8
Nodules in earlobe	5
Paralysis of eyelid	5
Others	4

Causes of leprosy

Out of the 30 AWWs, 20 correctly stated that leprosy was caused by germs. Six stated that they did not know the cause of leprosy, and four provided less precise answers such as caused by a skin disease, by air, or by the low preventive power of the body. However, since 33% of the respondents did not state the correct cause of leprosy, more training was considered necessary.

Table 8: Causes of leprosy

Cause	Total (N=30)
Curse	-
Hereditary	-
Germs	20
*Others	4
Don't know	6

* Skin disease, by air, low preventive power of the body

Affected parts of the body

Only about one-third of the respondents explicitly mentioned skin and/or nerves as the affected parts of the body. The category of "Others" generally consisted of references to different sites on the body instead of parts of the body, indicating implicit reference to the skin.

Table 9: Affected parts of the body

Part of the body	Total (N=30)
Skin	13
Nerve	13
Others	13

Note: Multiple answers were given by respondents

Referral

Although the AWWs were trained about the signs and symptoms for referral during treatment, they could not list these correctly after six months of the training. Nine out of 30 respondents stated that red-coloured urination was a symptom for referral, which was not correct, whereas the correct symptoms for referral were not known to a large proportion of the respondents.

Table 10: Referral symptoms according to AWWs

Symptoms	Total (N=30)
Red-coloured urination	9
Irritation of the body	8
Change of body colour	2
Yellow eye colour	4
Swelling of joints	8
Boils in the body	5
Red painful nodules	1

Treatment

Eighteen respondents stated that the disease was curable by MDT, and 12 said it could be treated by medicines. Two respondents added a timeframe for medication. However, all AWWs stated that leprosy was curable with medical treatment. Furthermore, 29 out of the 30 correctly stated that if not treated, leprosy could lead to deformity.

Table 11 : Treatment of leprosy

Treatment method	Total (N=30)
MDT	18
Medicines	10
Medicines in between 6 to 12 month	1
Medicines for 6 months	1
Don't know	-

Types of leprosy

Twenty-two respondents out of 30 stated that SSL, PB and MB were types of leprosy and four mentioned only PB and MB. If both these answers are accepted as correct, it follows that four of the respondents were not able to list the types of leprosy correctly.

Table 12: Types of leprosy

Types	Total (N=30)
MB	-
Both MB and PB	4
MB, PB and SSL	22
More than above	3
Don't know	1

Diagnosis given to patients

The training included advice to be given to patients during treatment. This component was reflected adequately during the interviews with the AWWs. However, only 18 of the 30 respondents would use the word “leprosy” when informing patients of the diagnosis (Table 13). This indicated that leprosy remained a stigmatised illness, but it was not clear whether it merely pointed to a hesitation on the part of the AWWs, or whether they deliberately used other concepts in order to overcome barriers to treatment on the part of their patients.

Table 13: Words used by AWWs to describe illness when informing patient

Disease	Total (N=30)
Leprosy	18
Patch	8
Big disease	2
Skin disease	1
White patch	1

Suspicion, referral and treatment

The new role of AWWs involved identification of possible cases, referral for examination and MDT treatment. It was observed that 27 of the 30 AWWs had been involved in case suspicion, either after the intervention or in connection with MLEC/LEC. These 27 AWWs had suspected 167 cases, out of which 110 cases were sent for examination. The reasons for not being examined included the work timings and/or negligence. Sixty-three of the 100 cases were diagnosed as of leprosy and MDT was

started in 62 cases. These results indicated that the new role given to AWWs to suspect, refer and treat had been adopted satisfactorily.

IEC

The AWWs stated in the interviews that they communicated leprosy issues when interacting with the community. These included early signs and symptoms, causes and treatment during mothers' meetings and home visits. This could lead to increased case-detection in the community, particularly if AWWs' knowledge of these issues was strengthened.

Record and report

All the AWWs maintained records and registers and submitted the monthly progress report at the monthly sector meeting to the PMW.

Twelve patients were interviewed to assess the impact of the intervention as seen from the patients' perspective. Eight were PB and four were MB cases. Of the 12, five were men and seven women.

6. Patients' Perspectives



All the 12 patients stated that they regularly got MDT drugs from the AWCs. Hence, the distribution of MDT as stated by AWWs was confirmed by the patients.

Four patients expressed problems with MDT drugs, indicating side-effects like red-coloured urination and head-reeling (dizziness).

Table 14 shows that there was no uniform pattern concerning who informed the patient that he/she was suffering from leprosy. The fact that leprosy may be also named as 'patches', etc., makes it difficult to interpret these findings. Concerning suspicion of leprosy, the picture points to a tendency towards suspecting leprosy within the household, as eight of the 12 patients stated that they themselves or their relatives first suspected the disease.

Of the 12 patients, 11 reported that within one year of the appearance of symptoms they were diagnosed as having leprosy. In one case,

Table 14: Case-suspension and diagnosis

	Who told that patient is suffering from leprosy?	Who first suspected leprosy in your case?
Self	-	5
Family members	2	3
AWWs	2	2
PMWs	4	2
Govt. Hospital	3	-
Others	1	-
TOTAL	12	12

diagnosis was made in a private clinic five years after the first appearance of leprosy symptoms.

According to the interviews, none of the patients faced any serious problem of being ostracized or otherwise stigmatised during the course of treatment. However, one patient reported that he had been previously teased by schoolchildren because of his leprosy but that now he was tolerated. In another case, the patient had been motivated by her husband to continue medical treatment.

None of the respondents had faced any problem in getting medicines from the AWCs.

In summary, the following points were made by patients:

- Access to MDT had increased after the intervention due to drug availability at almost all *Anganwadi* centres.
- A considerable delay in diagnosis and treatment was found prior to the intervention. Delay in diagnosis is expected to be reduced as a consequence of increased access to treatment.
- AWWs were not sufficiently aware of the signs and symptoms and causes of leprosy and the reasons for referral. This indicated a need for further training.
- Involvement of AWWs was found to be very positive, partly due to their earlier association with LEC and MLEC.
- All 12 patients stated that they received MDT regularly from AWCs.
- Patients generally reported other sources of information than AWWs.

7. Conclusion and Recommendations



The study showed that MDT delivery can effectively be integrated into the ICDS system. However, a note of caution may be added, since the workload of AWWs The study showed that MDT delivery can effectively be integrated into the ICDS System.However a note of caution may be added, since the workload of AWWs will increase as more and more specialised health interventions come to rely on them. In addition to leprosy, they may be involved in the TB DOTS programme, in malaria prevention, as well as in immunization campaigns. Hence, while the present study suggested that the Joda intervention may be replicated in comparable situations, there was a need to consider the overall workload of AWWs when doing so.

Recommendations

1. Reorientation and refresher training should be established for AWWs on leprosy, with special focus on its symptoms, referral and causes.
2. IEC activities should be strengthened.
3. An LEM or a follow-up study should be conducted after two years to assess the impact of delay in diagnosis and treatment of leprosy.
4. The intervention should be replicated in comparable bigger urban areas.
5. A health systems research study should be conducted to assess the overall role of AWWs, including issues of gender, workload, network, remuneration, needs and work satisfaction.



A profile of 35 patients under treatment in Joda, June – December 2002

Location of AWC	Pt ID	Sex	Type	Symp-toms onset	Diagno-sed	Delay in diag-nosis	Approx. aerial distance to Govt. Hosp. (km)
Talak Hatting	1	M	PB	Apr'i'02	July'02	3	4.5
Mukharjee Hatting	2	M	MB	Sept'00	Sept'01	12	3.9
Mukharjee Hatting	3	M	MB	Feb'01	Feb'02	12	3.7
Mukharjee Hatting	4	F	MB	Sep'01	Feb'02	6	3.8
Bapuji nagar Hating	5	M	MB	May'97	Oct'02	60	3.2
Ulli Hatting	6	M	MB	Feb'01	Feb'02	12	2.3
Ulli Hatting	7	M	MB	Jan'01	July'02	18	2.4
Ulli Hatting	8	M	PB	June'01	June'02	12	2.4
Ulli Hatting	9	M	PB	Jan'02	June'02	5	2.4
Ulli Hatting	10	F	PB	Jan'02	June'02	5	2.3
Ulli Hatting	11	M	PB	Apr'02	Sept'02	5	2.4
Hanuman Basti	12	F	MB	Sep'01	Feb'02	6	1.5
Hanuman Basti	13	F	PB	Mar'02	Aug'02	5	1.5
Kundurunala	14	M	PB	Jun'01	Jan'02	8	2.2
Ajad Basti	15	F	MB	Nov'01	Nov'01	0	2.8
Ajad Basti	16	F	MB	May'01	Nov'01	6	2.3
Ajad Basti	17	M	MB	Jan'00	Jan'02	24	1.5
Ajad Basti	18	F	MB	May'00	May'02	24	2.4
Ajad Basti	19	F	PB	Sep'01	Feb'02	6	2.6
Hudisahi	20	F	MB	Apr'01	Apr'i'02	12	2.6
Mati Hatting	21	M	PB	Mar'01	July'02	4	2



Location of AWC	Pt ID	Sex	Type	Symptoms onset	Diagnosed	Delay in diagnosis	Approx. aerial distance to Govt. Hosp. (km)
Mati Hatting	22	M	PB	Jan'01	Sept'02	9	2
Mati Hatting	23	M	MB	Jan'01	Jan'02	12	2
Penthai Sahi	24	M	PB	Feb'01	Feb'02	12	0.7
Murteja	25	F	PB	Jan'01	Aug'02	7	0.8
Gopa Mohanty H.	26	F	PB	Nov'01	June'02	6	1
Bansapani Basti	27	F	MB	Jul'00	July'01	13	1.3
Bansapani Basti	28	F	MB	Nov'00	Nov'01	12	1.4
Bichhakahandi H.	29	M	PB	Dec'01	Feb'02	2	1
Bichhakahandi H.	30	M	PB	Sep'01	Dec'01	4	0.8
Behera Hatting	31	M	MB	Jan'00	Feb'02	24	1.7
Penthai Sahi	32	F	PB	Dec'01	May'02	5	0.5
Penthai Sahi	33	M	PB	Aug'02	Oct'02	2	0.5
Penthai Sahi	34	M	PB	Jan'01	Sept'02	8	0.5
Ajad Basti	35	M	MB	Jan'01	Jan'02	12	2.3

Figure 4: Distance from MDT delivery point (Govt. Hospital) to patients' homes prior to the intervention

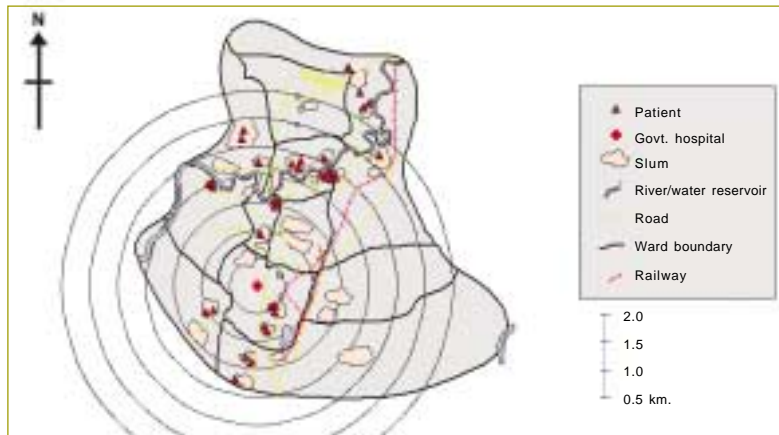


Figure 5: Distance from MDT delivery points (AWC) to patients after the intervention

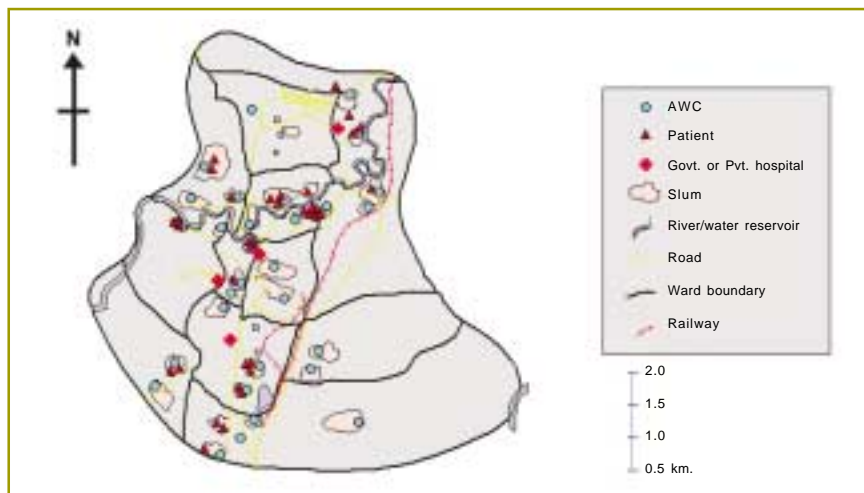


Table 10: Referral symptoms according to AWWs

Symptoms	Total (N=30)
Red-coloured urination	9
Irritation of the body	8
Change of body colour	2
Yellow eye colour	4
Swelling of joints	8
Boils in the body	5
Red painful nodules	1

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