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The Special Drive for Leprosy Elimination, Burhanpur



The Special Drive for Leprosy Elimination was carried out in Burhanpur as planned as a time-bound campaign. Since the main objectives of this initiative were awareness generation and information dissemination, the greater part of the initiative was comprised of IEC activities. The efforts of the core group, the principal stakeholders and other participants culminated in the commemoration of a leprosy fortnight. Almost all materials pledged towards the event were delivered. Groups and institutions (including local schools) ensured the presence and participation of their volunteers. The schedule of activities for the special initiative is given below.

Table 5: Activity schedule for special drive for leprosy elimination, Burhanpur, 2002

Month and Date	Activities
Jan 30	Rally by government schoolchildren
Feb 2 & Feb 3	<i>Dastak</i> campaign by volunteers from private and government groups and institutions
Feb 3 - Feb 9	Prevention of Disability camp organised by NLEP and private donors
Feb 10	Free Diagnostic and Treatment camp organised by the Burhanpur Medical Shop-Owners' Association

6.1 The leprosy awareness rally

On the occasion of Mahatma Gandhi's death anniversary on January 30, 2002, two rallies of schoolchildren belonging to various middle schools



Schoolchildren taking out a rally in support of the leprosy elimination campaign in Burhanpur.

in Burhanpur were organised. The first rally started with the children marching with placards carrying information on leprosy, chanting slogans from their respective schools. The rally converged at the Gandhi Chowk in Burhanpur at 10.55 a.m. The Mayor, the local Member of the Legislative Assembly (MLA), leading citizens and many other prominent people from the community addressed the rally. They praised the efforts of all those involved in the event and urged the people to do their part, however small, in aid of leprosy elimination. This was followed by an address by the Zonal Coordinator, DANLEP. He highlighted the social face of the disease and the taboos and ostracism faced by LAPs and appealed to the people to do away with such practices.

The second rally converged at Lalbagh at 12:45 p.m. The participants again were children from middle schools in the area and they too carried placards with information on leprosy and shouted slogans. The same group of dignitaries addressed these children and at the end both groups dispersed with the singing of the national anthem.

6.2 The *Dastak* campaign

Dastak is a door-to-door interpersonal communication activity in which all the households in the area are covered and informed about the disease, its causes and cure. The *Dastak* campaign was held on 2 and 3 February, 2002, at Burhanpur as part of the special initiative for leprosy elimination. A cross-section of people, including schoolchildren of various ages, NGO functionaries, youth groups and *Anganwadi* workers, were enlisted as volunteers for *Dastak*. The training of these volunteers

was conducted by the NLEP unit, Burhanpur, on 1 February and they were given brochures containing photographs of the symptoms of leprosy and information on treatment along with pamphlets informing about the skin diagnosis and treatment camp to be held on 10 February.

The volunteers were further divided into groups of four and two groups were assigned to cover each ward in two days. In addition, the volunteers had to conduct a survey to identify any new case of leprosy by filling a prescribed format and submit it to the NLEP. The volunteers were required to start at 9 AM each morning and work till 3 PM. They were requested to submit their reports by 4 PM every day. They were to knock on the door of each house in the vicinity, introduce themselves to the residents, inform them about the reason for their visit, collect as many family members present at the time and inform them in detail about leprosy. After this they were to ask the members present whether they had any spots or patches on the skin, and with their consent, perform an examination or ask the family members to examine each other. In case they were disinclined to allow an examination, the volunteers were to inform them of the nearest NLEP unit for undergoing a check-up. They were also to inform them about the skin diagnosis and treatment camp scheduled for 10 February where services of doctors as well as medicines were available free of cost.

The campaign was monitored and managed by the local NLEP functionaries.

A review of the *Dastak* volunteers

Interaction with people

The *Anganwadi* workers were found to be the most active as well as most forthcoming with any kind of information. Other members in the group adopted a passive role. The NSS members or schoolchildren who were part of the team generally did not interact much. They usually stood by, quietly watching others.

The role of the *Anganwadi* workers and the NGO/community/religious groups seemed more clearly defined than that of other members. The *Anganwadi* worker, who also filled up the NLEP survey form, usually delivered the information on leprosy. The NGO representatives/

community members/religious group volunteers usually helped the *Anganwadi* worker to fill gaps in information, if any, and also assisted them in filling the survey form. The NSS/school children usually handed over the pamphlets containing information on the skin diagnosis and treatment camp.

Awareness level of volunteers



Volunteers getting ready to make home visits as part of the *Dastak* campaign.

Discussions with the volunteers revealed gaps in their level of knowledge about leprosy. While they were aware of the basic symptoms of leprosy, which they had learned in the training provided prior to *Dastak*, they were often unable to differentiate between leprosy and non-leprosy symptoms if these had similar visual manifestations. For instance, the volunteers were aware that an anaesthetic, colourless patch on the body was a symptom of leprosy, but a significant number of suspected cases had patches with sensation. Lack of sufficient knowledge about the signs and symptoms of leprosy resulted in their being unable to clarify doubts raised by the people. None of the teams participating in the discussion claimed to have spent more than three to four minutes with the families they visited.

The volunteers constantly expressed problems in being able to ask the respondents if they or anyone else in their families had leprosy. This seemed to be a result of lack of sufficient orientation coupled with the fact that even they had not become comfortable with the notion that leprosy is a bacterial infection that has no connection with lifestyle or social stratification. As a result, most of the interactions ended at the door, where just one person from the family would speak with them. In many cases the *Anganwadi* workers seemed to assume that there was no need for further information, especially since they frequented these houses as part of their routine work and they had not seen anyone with such a complaint.

Confusion with leucoderma was a common problem for the volunteers. This often resulted in misinformation, when they convinced people with leucoderma that this was a curable condition.

Another area of concern was that they referred all suspected cases to either the Urban Leprosy Centre (ULC), which is not conveniently located for all households, or the proposed Skin Diagnosis and Treatment camp, which was a one-time occasion. Most of them did not know of other NLEP units in the town, which would be closer to the area. Another vital information that they overlooked was to inform the people that medicines for leprosy would now be available at the Outpatient Department (OPD) of the district hospital.

Suggested modification for *Dastak*

1. Selection of the members of the National Service Scheme (NSS) and Scouts and Guides and schoolchildren as volunteers for *Dastak* can be explored further, since they have certain advantages in terms of acceptability and access to households (especially when wearing their uniforms). This group may also be less inhibited in comparison to other categories of volunteers, and has a good capacity for learning and imparting information. However, the Burhanpur experience also points to limitations, as the children were watching interaction with people from the sidelines and generally were not able to assert themselves during case-detection. Furthermore, they need more training than people from the health sector, and it is difficult to ensure accountability of these young people.
2. The number of households to be covered needs to be drastically reduced and/or the time apportioned for visits should be realistically planned. Instead of conducting this in a rapid mode, the exercise could be carried out over a period of three-to-four months by covering a few houses every day with more thoroughness. This would also provide an opportunity for the volunteers to fill the gaps in their own facts and interact better with the people.
3. The training given to these volunteers should be more comprehensive. Reinforcement sessions should be held with adequate interval before they begin the *Dastak* exercise. The training

should cover aspects like how to introduce oneself, the method of opening discussions with families arousing least resistance from them, means of tackling difficult situations that they could be faced with, etc. In addition to information about leprosy, a basic idea of the health service delivery system should also be given so that when faced with queries regarding other ailments they are able to guide the people to hospital. For instance, the names of departments that deal with various ailments so that the information they give could be more specific.

Prevention of Disabilities camp

The POD camp was held in Burhanpur from 2–7 February 2002. The Non-Medical Supervisor (NMS), Burhanpur, had organised the camp with help from individuals who agreed to meet all expenditure that would be incurred. As a part of this agreement, Anand Bhawan, a hall owned by the Sthanakwasi Jain Samaj Trust (a religious organisation), was given free of charge for use as the venue for the camp.

Two individuals covered all expenses for food for the seven days of the camp. A local milk trader supplied milk free of cost

The camp started work the next day at 9 a.m. with Hydro-Oleo-Physio-Exercise (HOPE) as group exercises after breakfast. This was followed by a small period of rest and then another HOPE exercise session, following which they assembled for lunch. At 3 p.m. following lunch and rest, there was another HOPE exercise session. The patients were then assembled at the open space in front of the building for the self care session and the NLEP functionaries and volunteers.



A leprosy-affected person sharing his experiences at a Prevention of Disabilities camp.

NLEP functionaries did counselling about changes to be adopted in lifestyle and self care all through the day during the sessions, regaining self esteem lost by LAP.

On 4 February 2002, the only variation in activity was the visit of the local Member of Parliament (MP), Mr. Nandkumar Singh Chauhan, who interacted at length with the organisers and patients. He stated that any help required from him would be extended to the leprosy elimination initiative.

The total expenditure on the POD camp was approximately Rs. 15,000/- according to the organisers, which was considered a large amount, in addition to the time devoted by the sponsors and their families.

Observations on the POD camp

1. The camp was well-organised in terms of accommodation, food and other requirements of the participants.
2. It was a good example of coordinated efforts between a government department like the NLEP and the community, represented by the sponsors. All arrangements were carried out after joint deliberations and the existing rapport between the two parties ensured smooth running of the camp.



Female leprosy patients receiving special footwear during the treatment camps.

3. The camp was well-covered by the city cable unit as well as newspapers, and this was largely ensured by the MP's visit to the place following efforts by DANLEP to convince the city cable unit to cover the event and the sponsors' invitation to the MP.

6.4 Free Skin Diagnosis and Treatment camp

A large-scale skin diagnosis and treatment camp was held on 10 February 2002 at Gandhi Bhawan in Burhanpur. The Burhanpur Medical Dealers' Association (BMDA) organised the camp. It aimed at providing diagnostic and treatment services to patients having skin ailments.

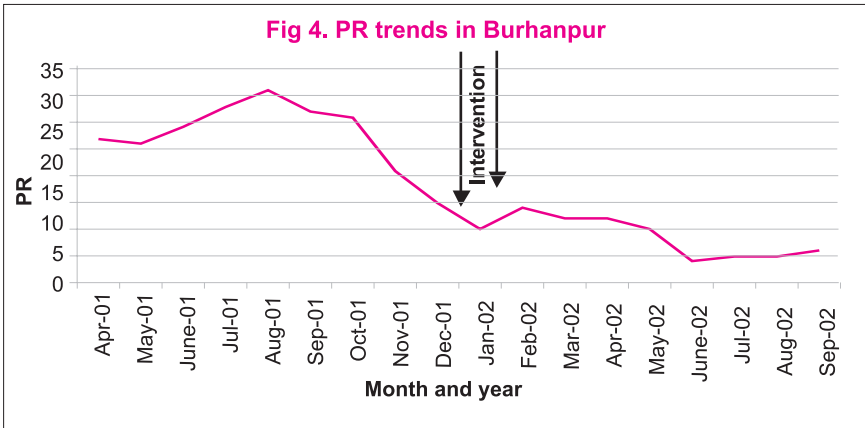
The *Dastak* campaign conducted earlier in the week was one source of identifying patients and motivating them to attend the camp. In addition, information about the camp was announced through loudspeakers fixed on two horse-drawn carriages moving around in the town. Doctors for this camp were invited from the district and town health departments, the NLEP unit, Burhanpur, and DANLEP MP. The BMDA supplied medicines free of cost to all patients who attended the camp.

Observations

1. The camp was a good example of what could be achieved if various stakeholders cooperate and carry out activities in areas where each can contribute according to capability.
2. The main shortcoming in the activity was the absence of active involvement of the Health Department in camp arrangements. The large number of volunteers as compared to the limited number of health professionals resulted in overlooking important issues like the presence patients' privacy during a physical examination.

6.5 Outcomes

Information dissemination, while being one of the main objectives, was specifically addressed in two ways: 1) Through daily newspaper coverage of all the programmes held during the special initiative, with detailed information on leprosy, its causes and cure. The local daily, Burhanpur Samachar, published these messages free of cost ; 2) The recording and release of an audio cassette, which contained a dramatic



PR trends in Burhanpur before and after the special initiative
Source: NLEP-MP and DLO, Khandwa district

presentation of various issues involved in leprosy elimination in Hindi. This was inaugurated on the first day of the POD camp. The entire venture was undertaken at a minimal possible cost and was sponsored by a local businessman.

The outcome of these activities and efforts went beyond the fortnight. The Lions, Lionesses and Rotarians stated that if proper guidance was available, they were willing to organise skin diagnostic camps on a quarterly basis both in Burhanpur and in the peripheral areas. The current chairperson of NIMA volunteered to adopt five villages for initiation of case-identification and provision of patient care. Institutions like the Unani and Ayurvedic medical colleges, represented by their deans, stated that they would incorporate leprosy case-identification, registration and patient follow-up as a part of their curriculum as a sustainable support activity to the existing system.

An important element in the entire initiative was the coordination between various members of the core group who put personal agendas on hold to ensure that the campaign was not influenced negatively. Roles by each member of the core group were voluntarily assumed and, once assumed, there was an unspoken agreement that no one would cross into the other's territory.

An impact assessment had not been planned for the post-campaign period. This was primarily due to lack of time and resources to undertake

Table 6: The Burhanpur special initiative at a glance

Medical camps	Doctors providing services	10
	Patients attending	538
	New leprosy cases detected	12
Rallys	Persons (adult and children) attending	18,980
POD Camp	Leprosy affected persons admitted	47
	Rs. contributed by community for meals	28,590
<i>DASTAK</i>	No. of volunteers participating	702
	Population covered	200-250,000
	New leprosy cases detected	3
Skin camps	No. of beneficiaries	355
	New leprosy cases detected	9

such an exercise. However, a successful intervention is expected to lead to an immediate increase in PR due to the special case-detection efforts. As can be seen in Fig. 4, there was in fact a measurable increase in PR immediately following the initiative, as well as a further decrease in PR following a six-month treatment period, indicating a successful intervention within the population that was, in fact, reached by the initiative.

Follow-up visits undertaken in June and November 2002 by DANLEP revealed that the citizens and stakeholder groups of Burhanpur were still active in their efforts towards leprosy elimination, with intermittent support provided by the NLEP and the GHS. The following chapter details the future plans for leprosy elimination in Burhanpur.