



ILEP



TECHNICAL BULLETIN

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DETECTING HARD TO REACH LEPROSY PATIENTS

1 INTRODUCTION

At the beginning of 1997, about 890,000 leprosy patients were registered for chemotherapy, globally. The World Health Organisation estimates that the true prevalence of patients in need of chemotherapy is about 1,150,000 patients. This estimate was reached through information provided by national programme managers from endemic countries, taking into account registered figures, health service coverage and MDT implementation. This means that there would presently be a gap of about 260,000 undetected patients. This is an approximate figure, since population surveys conducted in different areas often showed that there were two to three times more patients than reported through the registered figures.

All leprosy control programme managers should have high on their list of priorities to explore whether they are facing a problem of under-detection, and if so, what could be the reasons for it. A high percentage (> 10 %) of patients with grade 2 disabilities among the newly detected cases or a huge gap between registered and estimated cases are signs of under-detection.

A questionnaire was sent in 1996 to the ILEP Member Organisations, asking them to mention the strategies that were adopted to overcome problems that limit access of the patients to diagnostic and treatment facilities. Many leprosy control managers have also developed proposals for SAPEL projects.

2 ASSESSMENT OF THE PROBLEMS

Two types of situation may exist.

2.1 Leprosy services are available

Here, undetected patients live in areas where general health services and/or leprosy services are available, including services supported/run by ILEP member-organisations. This is probably the most frequent situation. It should be possible to detect and treat these patients through intensifying

or improving the effectiveness of the existing services. A better integration of the leprosy services into the general health structures may be the key to success. Special, time-limited activities, such as LEC's, can boost the effectiveness of these services. It has been seen in some instances, even in areas thought to be well covered by health services, that such intensive campaigns could detect in a short period, significant numbers of hidden cases. Such a campaign was launched in three districts of West Java, Indonesia, for example. It detected in a few weeks, more than twice as many cases than during the whole previous year. Fifteen percent of these newly detected cases had grade 2 disabilities.

2.2 Leprosy services are not available

In the second type of situation, the undetected patients live in areas where no service is present or adapted, because of external constraints. For these patients, special, innovative solutions may have to be found, adapted to local needs.

Before launching a special strategy, one should thus examine whether the undetected patients really belong to a specific group of the population who, for various reasons, cannot be reached by available health services, or whether they remain undetected just because of poor management of these health services. If the latter is the case, then the solution will be found in improving the quality of the existing health services, and not in implementing new, special actions.

It is only advisable to adopt special strategies to reach some specific groups of patients if and when normal and satisfactory facilities are available for the rest of the population. This is for reasons, first of simple equity, and second, of cost-effectiveness. It is often the case that designing special strategies to reach a sometimes limited number of patients may be relatively costly. This is absolutely acceptable but it should not be done at the expense of the normal control programme.

In some cases, the only solution to reach and treat patients may be to relax otherwise more stringent

requirements. One should always be careful, if adopting these special strategies, to see that they do not become the rule and are generalised to all patients. If this was so, it would quickly result in a loss of quality for the whole programme.

Sustainability is also a crucial point to consider when deciding to launch special actions. From a public health point of view, the impact of offering special leprosy services to a population might be marginal, if these services are only available during a very limited period of time. It takes years of sustained action to have an impact on transmission of the disease.

3 EXAMPLES OF PROBLEMS AND SOLUTIONS

The reasons cited for patients remaining undetected/hard to reach are multiple. They are often interrelated. The main problems may lie in:

3.1 The health services

- Non-existent health care structures or leprosy services, or absence of trained staff, or poor motivation of staff.

Example: In Rashad Province, Sudan, a project was launched in a remote area affected by civil war since 1985 and where there are no functioning health facilities. Social stigma is also high for leprosy. A mobile team periodically visits the villages, providing health education to village leaders and the community, screening suspected cases, examining household contacts and initiating MDT for detected cases. A total of 18,212 persons were examined, and 193 cases were detected. Drugs were given for six months to PB patients, and for one year for MB cases, their intake to be supervised either by the local health worker or the village leader.

- Unadapted health services.

Example: In Yunnan Province, China, leprosy workers who could speak the community dialect are used to train village public health workers and township public health workers for suspecting leprosy cases and management of diagnosed cases. A referral system is created at the county/prefectural levels for confirmation of diagnosis and management of complications.

- Inappropriate management of patients by practitioners not involved in the leprosy control programme.

Example: In Bombay, significant numbers of patients are treated by dermatologists. These practitioners are often not following the guidelines for diagnosis, classification and treatment. It was decided to involve them in the programme through appropriate training, clinical guidance and other technical support (skin smears services, clinical expertise for difficult cases, provision of facilities for recording and reporting, provision of literature on leprosy).

3.2 The community

- Insecurity, war.

Example: In Angola, church persons have been involved in the diagnosis and treatment of leprosy patients living in areas held by rebels and where there was no health infrastructure nor any leprosy control activity.

- Refugees.

Example: About 400,000 Mozambican refugees, including some 35,000 school children lived in 6 refugee camps in Shire valley, Malawi. The estimated leprosy prevalence was about 10/10,000. Staff provided by the Seventh Day Adventists and from the programme in Karonga were used to survey, detect and treat children.

- Mobility: Nomads, seasonal workers, sailors.

For these populations, besides undetection, the main problem usually consists in poor compliance to treatment for the required duration.

Examples: In Irian Jaya, Indonesia, it was decided to give blister calendar-packs for up to 6 months to patients belonging to migrating Papua tribes.

In Nepal, there is an influx of a high number of Indian patients who default and cannot be retrieved from across the border. Contact will be initiated between the leprosy control programmes of Eastern region in Nepal and of Bihar State in India, in order to exchange information and to be able to follow-up these patients.

In Chad, community leaders of nomadic populations, and resource-persons chosen by the populations themselves, have received orientation for the suspicion of early signs of leprosy, the delivery of treatment and supervision of drug intake. The resource-persons received 12 monthly packs per MB patient and 6 monthly packs per PB patient. Some sugar and tea were also given to the

resource persons and community leaders to motivate them. The size of the exposed population was estimated at about 72,000, and 44 patients (among whom were 32 new patients) have been put on treatment and followed by the 21 resource-persons.

3.3 Population sub-groups

- Women.

Example: In Hyderabad, the capital-city of Andhra Pradesh State, in India, it was very difficult to examine women of the Muslim community. It was decided to employ local women in the leprosy control teams in order to be able to reach also the female population.

- Tribal people and ethnic minorities.

Example: In some mountainous areas of Viet Nam, people from ethnic minorities who speak the local language are trained to suspect cases in their communities, and to collaborate in the drugs distribution and supervision.

- People living in urban slums.

Example: In Rio de Janeiro, Brazil, the leprosy control programme is inaccessible to people living in some slums. It was decided to open new clinics which are more accessible to the slum populations.

3.4 The geography of the area

- Difficult or non-existent roads.

Example: In the State of Amazonas in Brazil, many rural populations are scattered along the river banks, in areas where the population density is very low and no leprosy services are available outside towns. It has been decided to train rural health agents (who had been mainly contracted for the anti-cholera campaign) and community members. The aim is to use them for suspecting cases and being involved in case holding and health education activities. The patients have only to visit the Town Health Centre for confirmation of diagnosis and for treatment of complications.

- People living on hills, or on isolated or faraway islands.

Example: In South-Sulawesi, Indonesia, co-operation between different programmes has resulted in equipping a boat that is used for combined supervisory visits.

4 SUMMARY OF POSSIBLE SOLUTIONS

As seen from the examples above, the solutions could be schematically summarised as:

- Strengthening integration into primary health care and use of peripheral general health workers.
- Involving community leaders, volunteers and patients affected by leprosy for suspecting cases, distributing drugs, supervising the effective intake of the drugs and increasing community awareness.
- Distributing blister-packs for more than one month to the patients and giving them responsibility for regular treatment.
- Use of special teams for training, health education, confirmation of diagnosis, initiation of MDT and supervision.
- Collaboration with other programmes for diminishing some costs (transport, for instance).

5 CRITERIA TO ASSESS NEW PROPOSALS

The following list of questions should help to critically review proposals:

- Has the problem been correctly identified? How?
- What is the size of the population and the number of patients potentially concerned?
- What are the objectives and targets?
- Is it a situation requiring innovative solutions, or can the problem be solved through a better organisation of existing services?

If it requires special actions:

- Is there a clear and adequate plan of action, including a time-table?
- Does the proposed solution seem realistic and feasible? Can it be successful? Is it acceptable to the population?
- Were potential or actual partners (community members, local associations) involved in the preparation of the plan?
- Is the budget reasonable and justified? Is it cost-effective, with regard to the number of patients who will potentially benefit from it?
- How will the results be evaluated?

- Will it be possible to reproduce/expand this project to other areas?
- What will be the impact of the project, including side-effects, on regular programme (diverting attention and staff, for instance)?
- Is it technically and financially sustainable at medium or long-term? Is there a plan for progressively integrating the project into the normal routine programme?

6 CONCLUDING REMARKS

A joint WHO/ILEP workshop on Reaching Undetected Leprosy Patients in Endemic Countries took place in Geneva on 18-19 July 1997. The main recommendations of the discussions were the following:

- In the effort to reach undetected cases, the primary health care system should be strengthened by:
 - Training all health care staff in diagnosis, treatment and care of patients (capacity building measures for local health workers to improve MDT services.)
 - Involving other non-leprosy NGOs, local leaders, volunteers and their communities.
- Initiatives and special campaigns like Leprosy Elimination Campaigns (LEC), Special Action Projects for Eliminating Leprosy (SAPEL), etc. should be implemented within the national leprosy programme, particularly in difficult areas.
- Particular emphasis should be given to sustainability on the completion of special actions:

- All potential partners, technical and financial, should be involved starting from the early planning stages
- Special projects need not all be directed to WHO for funding but information regarding these activities should be reported to all concerned parties.

- Encourage the wider use of leprosy elimination monitoring (LEM) to measure access to MDT and success of the programme using indicators of
 - Drug supply.
 - Patient care.
 - Leprosy elimination .
- Organize national leprosy campaigns involving, on a larger scale, local NGOs, media and politicians, well-known figures, as well as people affected by the disease to demonstrate that they can lead a normal life.
- Improve information systems to identify areas needing attention, for example through the use of Geographic Information Systems (GIS).
- The coordination of activities is essential. A regular meeting at the initiative of Governments with local and international agencies should be held at least annually.
- In promoting collaboration and monitoring progress towards reaching undetected patients, a joint Workshop between ILEP, WHO and the National Programme Managers should be held once a year.

ILEP is a Federation of autonomous anti-leprosy associations. The text contained in this report is not binding on ILEP Members.

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