



ILEP



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## DETECTING HARD TO REACH LEPROSY PATIENTS

### 1 INTRODUCTION

According to figures reported to WHO by national programmes, about 245,000 new leprosy patients were detected in 2009, globally. After a dramatic decrease in case detection between 2001 and 2006, the diminishing trend has been much less marked since then. It looks as if an almost stable situation has been reached in the last few years. However this does not mean that the detection of all new leprosy cases is now timely. In many countries, more than 10 % of newly detected cases already have grade 2 disabilities at the time of leprosy diagnosis, indicating late and probably under-detection. A number of surveys done locally also show that in some places there were many more patients than reported through routine data.

All leprosy control programme managers should thus 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.

### 2 ASSESSMENT OF THE PROBLEMS

In most places and countries leprosy services are now integrated into general health services, at least at peripheral level, and it is expected that diagnostic and treatment services are made available through those general health facilities. It is also expected that new cases and suspects will come out and consult voluntarily. The only population group for which a possibly more active strategy is clearly recommended is the (household) contacts of leprosy patients, who are known to be at high risk and must be effectively examined. Is this strategy effective?

Two types of situation may exist.

#### 2.1 General health services are available.

That is the most frequent situation. In those places, at least theoretically, diagnostic and treatment services should be available for most ailments, including leprosy. A problem of under- or late

detection may exist in some places. It might be due to lack of awareness of the early signs of leprosy in the population. Another reason might be the rarity of the disease with, as a consequence, a lack of expertise among the health staff, who might not even think of leprosy as a possibility any more. Other obstacles might be cultural (e.g. an ethnic group not willing to consult health services held by a different ethnic group, or services less accessible for women), socio-economic (cost of transport, consultation fee, loss of income) or fear of discrimination if the leprosy diagnosis is confirmed.

Awareness campaigns in the general population are thus still essential, particularly in places where leprosy is known to still exist. They should insist not only on the early signs of the disease, but also on its curability and on the fact that leprosy patients should not be feared or stigmatized. General health staff should be taught at least how to suspect leprosy. In endemic places, one should strive for having one staff, in each health centre, capable of confirming the diagnosis. A well functioning referral system is clearly an absolute necessity. Quality supervision, aiming at continuous on the job training, is also essential.

A policy of free of charge access for the poor to general health services could certainly help alleviate some obstacles. In places where ethnic minorities are present, the presence of some health staff belonging to those ethnic groups might also be beneficial.

In cities particularly, diagnostic capabilities of dermatologists might be improved through the organization of specialized lectures and conferences, or through the possibility for them to call on experts for problematic cases.

#### 2.2 General health 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. As mentioned in the Operational Guidelines of the Enhanced Global Strategy for Reducing the

Disease Burden due to Leprosy (2011-2015), “underserved populations refer to groups of people who live in difficult geographic area (forests, riverbanks, deserts, mountains) or have special characteristic that denies them opportunity for access (e.g., tribal, nomadic population, slum dwellers, immigrants, internally displaced due to war, civil disturbance, social unrest, economic or climatic crisis) or live in special facilities (e.g., prison). These groups may face difficulties in obtaining adequate health care because of poor health infrastructure; lack of information or because of discrimination they experience due to their social, political, cultural and economic background or because of limited transportation facilities.” 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.

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. Rather than special, one-time actions, one should thus strive for innovative measures as a first step towards more sustainable and cost-effective solutions. A review of all possible stakeholders, including developmental agencies working locally, might give the opportunity to develop useful collaborations.

### 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: a project in a remote area affected by civil unrest where there are no functioning health facilities. Social stigma may be high for leprosy. A mobile team may periodically visit the villages, providing health education to village leaders and the community, screening suspected cases, examining household contacts and initiating MDT for detected cases. MDT drugs can be given for six months to PB patients, and for one year for MB cases, their intake supervised either by the local health worker or the village leader

- Unadapted health services.

Example: Where leprosy workers who can speak the community dialect are used to train village public health workers to suspect leprosy cases and management of diagnosed cases. A referral system can be created for confirmation of diagnosis and management of complications.

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

Example: In urban areas significant numbers of patients are treated by dermatologists. These practitioners often do not follow the guidelines for diagnosis, classification and treatment. They can be involved 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: religious leaders can be involved in the diagnosis and treatment of leprosy patients living in areas of civil unrest and where there was no health infrastructure nor any leprosy control activity.

- Refugees.

Example: local staff can be involved in conducting surveys, detection and treatment.

- 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: blister calendar-packs can be provided for up to 6 months to patients belonging to migrating populations.

In frontier areas where people default and cannot be retrieved from across a border. Contact can be initiated between the leprosy control programmes on each side of the border to exchange information and to follow-up these patients.

Community leaders of nomadic populations, and resource-persons chosen by the populations themselves, can receive 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. The resource persons and community leaders may need motivation.

### 3.3 Population sub-groups

- Women.

Example: In some areas it is very difficult to examine women from specific religious communities. Local women can be used in the leprosy control teams in order to be able to reach also the female population.

- Tribal people and ethnic minorities.

Example: In some areas, 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: the leprosy control programme is sometimes inaccessible to people living in some slums. Clinics which are more accessible to the slum populations can be used.

### 3.4 The geography of the area

- Difficult or non-existent roads.

Example: Many rural populations are scattered along the river banks, in mountainous areas or on islands where the population density is very low and no leprosy services are available outside towns. Rural health agents and community members can be trained. The aim is to use them for suspecting cases and being involved in case holding and health education activities. The

patients may have visit referll centres for confirmation of diagnosis and for treatment of complications.

- For people living on hills, or on isolated or faraway islands, cooperation between different programmes can share a boat for combined supervisory visits.

## 4 SUMMARY OF POSSIBLE SOLUTIONS

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

- Strengthening integration into primary health care and use of peripheral general health workers.
- Collaboration with dermatologists.
- Multidisciplinary mobile teams periodically visiting insecure areas.
- 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.
- Employment of women and of people from ethnic minorities in health staff.
- 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).

### References

WHO – *Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy (2011 – 2015) Operational Guidelines (updated)*