# **Editorial**

# THE MANAGEMENT OF NERVE DAMAGE IN THE LEPROSY CONTROL SERVICES

Leprosy is an infectious disease which causes disability and deformity due to the damage of peripheral nerves. In the control of leprosy, as an infectious disease, the provision of effective and adequate chemotherapy to as many patients as possible is the most important single measure for interrupting the chain of transmission of the infection and for curing the patients. Today multidrug therapy treatment (MDT) is the most effective of leprosy.

The provision of MDT should be given top priority in the control of leprosy.

Early effective chemotherapy will also prevent the development of disabilities in many new patients. This is an indirect effect of anti-leprotic treatment.

At present there are several million people in the world who are disabled due to leprosy. To the patients, their families, as well as to the general public, deformities have often much more significant implications than the infection itself. Deformities may lead to stigmatization and ostracism. If resources are available, chemotherapy and care for established deformities may be given concurrently. For the individual patients these two aspects are often inseparable. In our opinion there is no room for rehabilitation services without effective treatment, i.e. MDT.

One may argue whether there is a justification for the treatment of established deformity, including the care of ulcers and reconstructive surgery, in the absence of such care for patients with deformities due to other diseases. We think that the rehabilitation services for leprosy patients should be an integral part of the general rehabilitation services in which all patients with deformities are included.

The *prevention* of disability and deformity is, however, certainly an integral part of the leprosy control services. One aspect in the prevention of disability is the early detection and appropriate treatment of reactions which involve the nerves. Another means of control of disability is health education which is aimed at the promotion of self-care by patients.

This Editorial will concentrate on how the following two aspects can be handled by the leprosy control services:

The early detection and appropriate treatment of nerve damage and reaction; and The prevention of increase of disability in patients with irreversible nerve function loss before secondary complications have occurred.

We have chosen to concentrate on these two aspects for the following reasons:

The early detection of reactions is a responsibility of the leprosy control staff. A common idea is that a reaction occurs in the presence of nerve tenderness and pain. However, many reactions occur without these signs. If a reaction is treated promptly and adequately, irreversible nerve damage will be prevented or limited. Although it is common practice that patients who need treatment with corticosteroids are managed in hospital I think that, in particular for operational reasons, it is preferable that many of them are treated by paramedical staff in the field. Measures to prevent increase of disability in patients with irreversible nerve damage and before complication have occurred should be applied in the field. A common problem is the absence of a plan of action to apply disability prevention measures.

## The early detection and treatment of leprosy reactions

#### EARLY DETECTION OF RECENT NERVE DAMAGE

Recent nerve damage is damage to the nerves which has existed for a short period of time. This may have led to nerve function loss. The nerve damage can be reversed if appropriate treatment is given. Recovery of nerve function loss is likely when the loss has existed for less than 6 months. The sooner the damage is detected and treated, the better are the chances for recovery. In some instances, in particular in case of foot drop, recovery may still occur after 6 months.

Loss of nerve function loss may occur in an obvious way, or silently.

Obvious nerve function loss usually occurs quickly and is noticed and reported by the patients. It is accompanied by nerve pain and tenderness on palpation. There may be dramatic changes in appearances, such as foot drop.

Silent nerve function loss, however, can easily be missed, because it occurs without nerve pain, and often without the patient noticing nerve discomfort. There may be no obvious appearances due to muscle weakness. Changes in sensation are not visible and can only be detected by sensation testing. Sensation and/or muscle strength changes occur gradually over a period of weeks to months. Many patients fail to report these changes, unless they are specifically asked. They may think that these changes are an inevitable consequence of the disease or due to the anti-leprotic treatment. Loss of sole and palm sensation often occur silently. If not detected and treated in time these sensation changes may lead to lifelong problems of recurrence of wounds and wound complications.

Leprosy reactions and nerve damage may develop prior to the start of anti-leprotic treatment. The symptoms may be the reason for a patient to attend the medical services. Nerve damage may occur during the treatment; then it often occurs during the first few years after the start of chemotherapy. Nerve damage may also develop after the patient has completed a course of chemotherapy. BT patient especially, who have been treated with a 6-month course of MDT, may then develop a reactional episode after release from MDT.

#### SENSATION AND MUSCLE STRENGTH TESTING

In several manuals and textbooks the techniques of sensation and muscle strength testing are discussed in detail. We recommend the two books which are written by Jean M

Watson: Preventing disability in leprosy patients and Essential action to minimise disability in leprosy patients.

## Sensation testing (ST)

Sensation testing is done for the eyes, hands and feet. Sensation testing of the cornea is only needed when there are blink problems. If blink is normal, corneal sensation is normal.

On the soles and the palms a defined number of standard points should be tested. The number of points may vary from programme to programme. What is important is that the same points are tested everytime. In the ALERT Leprosy Control Programme 10 standard points on palms and soles are tested.

Sensation testing is usually done with the tip of a ballpoint pen. The touch should be light, just enough to dimple the skin. The pressure stimulus thus put on the skin can vary from 5 to 30 g depending, e.g., upon the thickness and stiffness of the skin and the way the pen is handled. A problem with the use of the ballpoint pen is that it is not possible to standardize the pressure stimulus put on the skin. To get a standardized stimulus on the skin some experts advise the use of monofilaments which apply different forces. At ALERT the 10-g filament was found adequate to detect loss of sensation in the sole.

Under routine field conditions the use of the ballpoint pen, although not a standardized method, is often preferable. A ballpoint is always available and there is no excuse for not doing sensation testing.

# Voluntary muscle testing (VMT)

For use in the field the muscle strength is usually graded as strong, weak or paralysed. *Strong*—full range movement in the joint and normal resistance.

Weak—full or partial movement in the joint and reduced resistance.

*Paralysed*—no movement in the joint and no resistance. When the eyelid is paralysed, the lid gap should be estimated.

It requires practice to learn the normal strength in the hands of, e.g., a young man, an old woman or a child. The strength of one side should always be compared with that of the other side.

Practical exercises in VMT and ST examinations should be included in the training and refresher courses of the staff. In addition, the performance of the staff should be assessed regularly by experienced supervisors and a physiotherapist, if available.

### Recording of findings

Results of VMT and ST examinations should be recorded on standard forms. Examples of such forms are given in the books written by Jean Watson and in the ALERT manual for field treatment of leprosy reactions.

Results of sensation and muscle strength testing at the time of diagnosis of leprosy should always be recorded, also if sensation and strength are normal. These so called baseline records should serve as the basis for a plan of action and for comparison with results of later examinations.

In order to limit the amount of paperwork, only those findings which are different

from previous examinations may be recorded. However, any changes in sensation and/or muscle strength, whether improvement or deterioration, should be recorded.

## The frequency of nerve function testing

Because recent nerve function loss can be reversed, ST and VMT examinations should be done at certain times and intervals. The interval can be different for different categories of patients.

Of course all patients should be examined at any time they present with complaints which can be caused by nerve function loss. It is our experience that with experienced staff and patients who have been exposed to the examinations, nerve function testing will not take more than 4 minutes per patient. We should like to stress that the examinations should be done routinely, whether or not a patient has any complaints. We experienced that over 65% of the patients who were found with recent nerve function loss did not present complaints spontaneously. When asked, some of the patients said that they had noticed loss of sensation and/or muscle strength; others had not noticed anything.

Another advantage of routine testing is that we do not have to rely on the observations of the patients. If proper records are kept the results of subsequent tests can easily be compared with those of previous examinations. Whether or not noticed by the patient, deterioration of nerve functions can be detected and appropriate action can be taken. ST and VMT examinations should be done: 1, at the time of diagnosis of leprosy; 2, during the course of chemotherapy; and 3, after release from chemotherapy.

### 1 At the time of diagnosis of leprosy

Nerve function loss which is found at the time the patient is diagnosed with leprosy should not be accepted as an irreversible condition. Especially in patients without deformities, loss of sensation and/or muscle strength may be reversible.

It is often not easy to obtain accurate and reliable information from the patient about the period the nerve function loss exists. We should take our time for questioning the patient. Sometimes it may be advisable to ask the patient to come back after 1–2 weeks and question him/her again.

If, from history, it appears that the nerve function loss exists for less than 6 months, the patient should be given a course of treatment that includes corticosteroid.

## 2 During the course of chemotherapy

Ideally sensation and muscle strength examinations should be done every month. If this is not possible, a frequency of testing of once every 3 months should be the minimum. During the initial phases of implementation of MDT, when the number of patients under chemotherapy is high, it may not always be possible to do the examinations with all patients at the defined intervals.

However, certain categories of patients should be examined at regular intervals:

New BT patients during the whole course of MDT, New BL patients, during the first 2–3 years of MDT, Women during pregnancy and during the first few mouths after delivery. With these patients VMT and ST should be done at monthly intervals. Other categories of patients could be examined less frequently.

# 3 After release from chemotherapy

New nerve damage which develops after release from chemotherapy may be a sign of a late reversal reaction or a relapse. It is often very difficult, if not impossible, to distinguish between a reversal reaction and a relapse. Since the clinical symptoms in both conditions are due to similar immune responses to mycobacterial antigens, the available techniques cannot give a conclusive answer. In the routine leprosy control services the appropriate treatment of new nerve damage should be given the highest priority. The diagnosis and treatment of a possible relapse is less of an emergency and should be considered after insufficient response to the treatment with a corticosteroid. I think that it is unjustified to wait for the results of several examinations which are aimed at reaching the most likely diagnosis, while not treating the patient for the new nerve function loss.

How often can we expect new nerve function loss after patients have been released from MDT? In the ALERT Leprosy Control Programme about half of the reversal reactions which were diagnosed in BT patients developed after release from MDT. However, it is very likely that more patients than we found develop new nerve damage after their release from MDT. This is based on our experience that in several patients, who did not have nerve function loss at the time of their release from MDT, irreversible nerve function loss was found 1 year or more after discontinuation of MDT. This observation has urged us to consider means of continuing the regular contact with BT patients after the 6 months of MDT. Because it has been experienced that after 6 months of MDT very few relapses occur, the treatment and the period of treatment can be considered sufficient to cure the vast majority of the BT patients. Therefore, continuation of chemotherapy after the 6 months of MDT is not needed or advisable.

In order to diagnose reactions at an early stage, patients should be seen at regular intervals for follow-up examinations. The usual recommendation for surveillance of PB patients is once a year for a period of 2 years. This frequency is certainly adequate for detection of relapses, but insufficient for the early diagnosis of new nerve function loss. I should like to recommend that BT patient be encouraged to attend for checkups at 3-monthly intervals during the first 1–2 years after release from MDT.

### The frequency of occurrence of reactions which involve the nerves

The frequency of occurrence of reactions is related to the type of MDT regimen. It is a general observation that ENL reactions occur less frequently in patients who are treated with the WHO-recommended MDT regimen, compared with other MDT regimens. It is likely that the anti-inflammatory action of clofazimine prevents ENL reactions.

In the ALERT Leprosy Control Programme we observed an increase in the number of patients who were diagnosed with a reversal reaction which affects the nerves, since the implementation of the WHO-recommended MDT. Such an observation should be interpreted with caution, because: available data about reactions during the days of dapsone monotherapy are incomplete; and the observed increase in reactions may well be related to better observations in the more closely supervised services.

Among 682 new patients we analysed the number of patients who developed a reaction which required treatment with a conticosteroid. The reactions were either diagnosed prior to the start of anti-leprotic treatment or occurred within the first year after the start of treatment with MDT.

The following results were obtained:

Class.	No. of new patients	Type of reaction			
		Reversal reaction		ENL reaction	
		No. of patients	%	No. of patients	%
TT	40	_	_		_
BT	304	60	19.7	1.0	
BL	249	105	42.2	12	4.8
BL	99	10	10.1	11	11.1
Total	692	175		23	

We can make the following conclusions.

Of the 198 reactions, 175 (88·4%) are reversal reactions and 23 (11·6%) are ENL reactions.

Of the 304 BT patients, 60 (19·7%) were diagnosed with a reversal reaction. Because several patients who developed new damage after release from MDT did not attend the services promptly, the actual number of BT patients who developed a reaction will be higher. The highest percentage of reversal reactions is found among BL patients; out of 249 patients  $105 (42\cdot2\%)$  developed a reversal reaction. Ten out of 99 LL patients ( $10\cdot1\%$ ) developed a reversal reaction.

Because the observation period was limited to 1 year after the start of MDT we can expect that with the extension of that period more patient will be detected with a reaction.

#### THE MANAGEMENT OF PATIENTS WHO NEED A CORTICOSTEROID

It is common practice that patients who need treatment with a corticosteroid are managed by a medical officer. This often implies referral of patients to a hospital. There is no doubt that corticosteroids can be dangerous if not properly used. Patients should be checked for contra-indications before a course of corticosteroids is started and for side-effects during the treatment. However, when the management of patients on corticosteroids is the responsibility of medical officers only, we will deprive many patients from adequate treatment of their reaction, because:

In many leprosy endemic areas doctors are scarce, and those available usually work at great distances from the homes of the patients;

Many patients are unable to be admitted for several months or to attend an outpatient department of a hospital. Common reasons are the family situation, work obligations, economic problems and lack of transport;

Hospital in- and outpatient facilities are often insufficient to provide services to all patient who need them.

We estimated that in the ALERT Leprosy Control Programme in the days when all patients who needed a course of prednisolone had to be referred to hospital, at least 60% of the patients did not receive the treatment. This was because either they were referred but did not go to hospital, they were not referred or they could not be admitted. We found that this situation had a negative effect on the motivation of the field staff to do regular ST and VMT examinations. Our observations urged us to develop a plan of action for the treatment of leprosy reactions in the field. A detailed manual for field treatment of leprosy reactions was written. Major responsibilities for the selection, treatment and follow-up of the patients were given to the leprosy control supervisors. After the staff had been trained, the treatment of reactions was introduced in three out of the twelve districts of the control area in early 1987. During the year thereafter the several technical and operational aspects of the management of the patients with a reaction in the field were supervised and monitored. As a result of this some procedures and technical aspects were amended. During 1988 the field treatment of reactions was extended in five districts. It is the intention that by 1990 the treatment will have been introduced in the whole control area.

## CRITERIA FOR TREATMENT WITH CORTICOSTEROIDS IN THE FIELD

In the ALERT Leprosy Control Programme patients with one or more of the following signs are considered for treatment with prednisolone in the field:

- 1 Pain or tenderness on palpation in one or more nerves, with or without loss of nerve function.
- 2 Change in VMT of less than 6 months duration. The change can be from strong to weak, from weak to paralysed, or from strong to paralysed.
- 3 Change in ST of less than 6 months duration. A change is considered significant when one finds:

*In a hand*: undoubted loss of ST in two or more points, occurring in the area of the same nerve trunk, i.e. either in ulnar or median area;

*In a foot*: undoubted loss of ST in two points or more.

#### PATIENTS WHO SHOULD BE REFERRED TO HOSPITAL

We defined ten categories of patients who should not be treated with prednisolone in the field, but be referred to hospital. These are patients who, beside recent nerve damage, have one or more of the following conditions:

Severe ENL.

Deep ulcer(s).

Nerve abscess.

Corneal ulcer, keratitis, iritis or iridocyclitis.

Suspicion of tuberculosis or any other systemic disease.

Positive urine test for glucose and or protein.

Recent nerve damage 1 year or more after release from MDT.

Pregnancy.

Age of less than 12 years.

Deterioration of nerve function while under 40 mg of prednisolone, the highest dose of the drug which is given in the field.

In case it appears impossible for a patient to go to hospital, or in case a patient needs some time to make necessary arrangements before going to hospital, some of the above categories of patients may be considered for treatment in the field or for initial start of corticosteroids in the field. This applies to patients with severe ENL, pregnant patients, children between the age of 6 and 12 years, and patients who develop nerve damage 1 year or more after release from MDT.

In order to rule out the conditions given above, a history is taken and the patients were examined prior to the decision about treatment with prednisolone in the field. Patients suspected of dysentery, found with conjunctivitis, trachoma or scabies are treated for these conditions in the field. Because many patients suffer from worm infestation, which may exacerbate under the treatment with prednisolone, all patients are routinely given a broad spectrum antihelminthic. History taking, examination of the patients, recording of findings, and the decision about the place of treatment are all responsibilities of the leprosy control supervisors.

#### CORTICOSTEROID REGIMEN

The most commonly used corticosteroid for the treatment of reactions is prednisolone. For the treatment of severe ENL usually a course of a few weeks duration is given. The recommended course for the treatment of reversal reactions varies widely in terms of the initial dosage and the duration of the treatment. At ALERT a course of 6 months duration, with an initial dosage of 40 mg prednisolone daily, was common practice. For operational reasons a 6 months course was considered too long for field conditions. We decided to give a standard course of prednisolone of 12 weeks duration, as follows:

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40 mg daily for 2 weeks,
30 mg daily for 2 weeks,
20 mg daily for 2 weeks,
15 mg daily for 2 weeks,
10 mg daily for 2 weeks,
5 mg daily for 2 weeks.
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After we observed that about one third of the BL patients who were treated with this course of prednisolone developed a repeat reaction, the period of treatment of BL patients was extended to 20 weeks. The course of the treatment for these patients was changed as follows:

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40 mg daily for 2 weeks,
30 mg daily for 4 weeks,
20 mg daily for 4 weeks,
15 mg daily for 4 weeks,
10 mg daily for 4 weeks,
5 mg daily for 2 weeks.
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#### RESULTS OF FIELD TREATMENT OF REACTIONS

From the experience we gained during the first 2 years of reaction treatment in the field, which was implemented by the leprosy control supervisors, we came to a number of observations and conclusions:

The majority of the patients can be managed in the field. Of the 198 patients who were diagnosed with a reaction, 144 patients  $(72 \cdot 7\%)$  were treated in the field, 42 patients  $(21 \cdot 2\%)$  were treated in hospital, 2 patients  $(1 \cdot 0\%)$  refused treatment and for 10 patients  $(5 \cdot 1\%)$  the data were incomplete. Most of the patients who were treated in the hospital were referred for an associate condition, some patients presented themselves at the hospital without referral.

In the 144 patients who were treated in the field no side-effects or complications due to the prednisolone were observed.

Of the first 55 BL patients who were treated with the 12 weeks course of prednisolone, 20 patients (36·0%) developed a repeat reaction. The repeat reaction either occurred during the low tail dose of the drug, at the end of the course or some time after finishing the treatment. In BT patients a similar problem was not observed. This confirms the finding by e.g. Naafs *et al.* (1979) that the antireaction treatment should be longer for BL than for BT patients.

The very fact that field staff can take action in case of reactions and often observe dramatic improvement within a short period of time, has had a positive effect on their motivation for doing regular ST and VMT examinations.

The attitude of the patients is very positive.

Field treatment of reactions has a positive effect on the esteem and credibility of the leprosy control services.

The results are satisfactory and encouraging. We classified the results as good, moderate and poor. Results are considered good if the patient got complete recovery of the nerve function loss which was found before treatment with prednisolone was started. Results are considered moderate if recovery of some of the nerve function loss was achieved. Results are poor if there is no recovery of the nerve function deficit. The results of the treatment were assessed immediately after the patient had finished the course of prednisolone. Of the 144 patients who were treated in the field, 12 patients had not yet completed their course of prednisolone at the time of assessment. Of the 132 patients who had completed the treatment, 105 patients (79·5%) achieved good results, 12 patients (9·1%) achieved moderate results and 15 patients (11·4%) poor results. It is possible that in the latter patients the reaction treatment was begun too late. In some we had to rely on the history for the duration of nerve function loss. Further recovery of the nerve function deficit may still occur after the course of prednisolone had been finished. This was not assessed.

An additional benefit of the management of patients with reactions in the field is that it is substantially less expensive than the management of patients with reactions in hospitals. This applies to the cost of the services, but also to the cost to the patients.

## The prevention of increase of disability in patients with irreversible nerve damage

#### IRREVERSIBLE NERVE DAMAGE

Irreversible nerve damage is damage to the nerves which cannot be reversed because it has existed for a long period of time. This is usually 6 months or more.

If recovery of nerve functions is not possible any more, measures have to be taken to prevent any further disability. If patients are detected at an early stage of the disease they are not yet disabled. Unfortunately, some of the patients have already established disability at the time of diagnosis of the disease.

In some leprosy control programmes, and in particular in those which apply active case-detection methods, less than 10% of the new patients are reported with a disability at the time of diagnosis of leprosy. However, in many programmes this figure is over 10%, even over 20%. Data about disabilities in new patients usually refer to those with a disability grade of 2 (WHO disability grading of 1988). Patients with a disability grade of 1 are often included in those without disability. This gives an incorrect picture about the magnitude of the disability problem. Patients with a grade 1 disability constitute a substantial proportion of those with disabilities. These patients are at risk of developing complications due to the nerve function loss.

In the ALERT Leprosy Control Programme we found that out of 856 new patients who were diagnosed during 1987, 532 patients (62·1%) did not have any disability, 166 patients (19·4%) had a disability grade of 1 (the highest disability of eyes, hands and feet) and 158 patients (18·5%) had a disability grade of 2.

# THE PREVENTION OF INCREASE IN DISABILITY BEFORE COMPLICATIONS HAVE OCCURRED

Health education which is aimed at the promotion of self-care by patients and the support of patients by their families is an important measure in the control of disabilities. This should be within the possibilities of the service which are responsible for the control of leprosy. During their contact with the patients the staff should take the opportunity to discuss with the patients how to protect their eyes, hands and feet and prevent them from injuries and wounds. If patients and their problems are taken seriously, this will increase their motivation to apply self-care measures. Patients should, as much as possible, be encouraged to buy their own Vaseline and oil. They should not be dependent on the distribution of these items by the medical services. This also applies to the provision of appliances for the protection of insensitive eyes, hands and feet. If footwear, which is suitable for insensitive soles, is available at the local market, patients should be encouraged to buy them. However, appropriate footwear is not always available, or is too expensive to be affordable. In several countries footwear programmes exist. Unfortunately, they often concentrate their attention on hospitalized patients, who already have foot deformities. The provision of footwear, which is designed to prevent the occurrence of wounds to outpatients, is often neglected. Or footwear is offered which is not acceptable because it identifies the patients as suffering from leprosy. Local shoemakers could be involved in making suitable and acceptable footwear. Since the majority of the patients with insensitive soles have normal shaped feet, standard size sandals will be appropriate for many patients. Where it is a rule that medical treatment should be provided free of charge, usually no funds are available for footwear. Or the funds are grossly inadequate. Also because people tend to take better care of appliances for which they have paid, a contribution by the patient would be an added advantage.

The provision of protective footwear by the medical services is a major undertaking. The selection of footwear which is suitable under the prevailing circumstances is one aspect. The availability of materials and financial resources are others. However, the planning and organization of a service which provides footwear without interruption and for life is the biggest and most difficult part of the undertaking. Footwear, although appropriate to protect insensitive soles, will hardly be effective if supplies are interrupted. If a continuous supply cannot be guaranteed, it is, we feel, better that footwear is not

offered by the services. Instead, the patients should be encouraged to buy the most suitable shoes at the local markets. So we come back to the promotion of self-care, through health education, as the most important and often the only available means of prevention of increase of disability.

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