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Editor's Choice

The article in this issue range across ethics, through self care and genetics to surgery so there should be something for everyone to enjoy.

Telling someone that they have leprosy is not an easy task and sometimes does not happen. John Porter and Anthony Zwei discuss the ethical principles of telling people their diagnoses in their editorial 'Ethical dilemmas in leprosy'. They raise the issue of setting concern for the individual against concern for the community and discuss how one might balance these. One of our long-term aims should be to reduce the stigma of leprosy so that telling them they have leprosy is not a dilemma.

The ethical and practical questions around HIV testing are discussed by Crampin and Damisoni in the HIV series. They highlight the potential benefits to an individual of knowing their HIV status and discuss the pre- and post-test counselling that should be done. Training and supporting counsellors is another important issue in programmes that offer HIV testing.

There are several papers and reports on managing disability in leprosy. Benbow *et al.* report on the self care groups that were established in Ethiopia. These were successful with groups taking up management and monitoring of wounds and participants reporting increased self-respect and restored dignity. Developing the groups involved changes for both the patients and the staff of the leprosy programme who had to change their roles from that of service provider to group facilitators. Not all groups were successful at working out how to maximize group success and sustainability will be critical to the future, wider success of this initiative. Another successful self care is reported from Nepal (paper by Cross and Newcombe) where patients have intensive training in appropriate self care, again with the aim of restoring self respect. In this programme, a short-term reduction in admissions with foot ulcers is reported. It will be important to follow these patients for longer to see whether this improvement is maintained.

The workshop on the neurologically impaired foot in Pokhara, Nepal June 2000 has generated two substantial reports, on assessment and examination and management of complications. These wide ranging reports are a useful contribution towards organizing concepts and definitions relating to foot problems in leprosy and will generate discussion and be useful to anyone managing patients with impaired feet.

Differentiating relapse from reaction in BT patients after multidrug therapy can be difficult. Dr Shetty and colleagues report their experience of isolating viable *M. leprae* from these skin lesions. Dr Waters has contributed a commentary on this problem reviewing the techniques of mouse foot pad innoculation and these particular results with suggestions for developing the work.

The next issue of *Leprosy Review* is the special issue to mark the publication of the *M. leprae* genome and will highlight the ways in which knowing the genome can help in understanding leprosy.

DIANA N. J. LOCKWOOD
EDITOR

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Editorial

NEEDING TO KNOW? ETHICAL DILEMMAS IN LEPROSY TREATMENT AND CONTROL

Summary A young man presents to your local clinic in a leprosy endemic country with a small patch of discoloured skin on his right forearm. The diagnosis is clear. You start to explain, but the man stops you: he doesn't want to hear more, just requests the medicine. But you are 'in conflict', and not just by the desire to discuss the situation more fully with your patient before prescribing a drug. The local public health team, of which you are a part, is currently evaluating the impact on the community's health of a patient education programme which necessitates informing all new leprosy cases of their diagnosis. What should you do? And can bio-ethics help?

Control of leprosy

This story will be familiar to many health care professionals who work in leprosy endemic countries. Clinically, the primary aim of intervention is to treat patients in order to achieve their cure, and to prevent the development of associated deformities. Broader objectives of leprosy control, however, are to interrupt transmission of the infection, thereby reducing the incidence of disease so that it no longer constitutes a public health problem.[1] Prompt treatment of all existing and newly detected cases with multi-drug therapy (MDT) is the principal method currently used.

The most cost-effective approach for case-finding is the promotion of self-reporting of suspect lesions through increased community awareness about the disease and this requires the patient to be informed of the diagnosis. This approach should be supported by efficient and easily accessible treatment services for the community.

Public health and the control of infectious diseases

For those of us working in the field of public health, our role is to work together 'to provide the conditions in which people can be healthy'.[2] Rather than simply focusing our attention on the individual, the patient above for example, our role is to also look at the health of the wider

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community, and decide how an individual case should be treated to provide the most benefit for the patient *and* for the community. A classical ethical dilemma in public health is whether to isolate an individual with an infectious disease – and therefore compromise his or her freedom – for the benefit of the population. This was the situation with leprosy before antibiotic treatment. In some countries, this approach has recently led to leprosy patients seeking compensation from the state for their 'draconian' treatment.[3]

Most situations are less clear cut than the classic textbook examples, and our man with the skin patch illustrates an important point. Public health interventions, like infectious disease control programmes, have the potential to embody an imbalance of power and capacity between the implementers and the recipients.[4] Health professionals decide when and where to intervene. It is presumed that whatever harm the intervention may impose on individuals is outweighed by the good it will bring to the population as a whole. This form of practice, this perspective, often tends not to exemplify respect for the autonomy of the people at the receiving end of the intervention.[5,6]

So, what are the questions we should ask ourselves as health care practitioners when deciding whether to tell a person that he or she has leprosy? What are the issues that we need to confront in order to ensure that we treat the individual with dignity and respect? If a person is found early with a skin patch and no other signs of disease, is it necessary to inform him or her of the diagnosis? By simply taking treatment an individual will be cured, and not revealing the diagnosis reduces the likelihood of being stigmatized by the community.

Ethics and principles

Proponents of bioethics tell us that ethics can provide a useful structure to help address these complicated problems of right and wrong actions in clinical medicine and public health. Ethics is the systematic intellectual endeavour to guide one's conduct by reason – that is, to do what there are the best reasons for doing – while giving equal weight to the interests of each individual who will be affected by one's conduct.[7]

Within bioethics, the approach labelled 'principlism' has come to dominate current international thinking in clinical and public health ethics. Principlism asserts that any medico-ethical dilemma, like the one above, can be tackled by reference to the following four principles: the principle of respect for *autonomy* (deliberated self-rule); the principle of *beneficence* (doing good); the principle of *non-maleficence* (doing no harm); and the principle of *justice* (fairness). The philosopher Raanon Gillon, an advocate of this system, has asserted that, along with attention to context, principlism provides a simple, accessible, and culturally neutral approach to thinking about ethical issues in health care.[8]

Using the four principles, a quick analysis of our case might look something like this. The autonomy of the patient needs to be considered and respected. According to the German philosopher Immanuel Kant, respect for autonomy means treating others as ends in themselves and never merely as means to some (externally defined) end. It is not therefore appropriate simply to treat and inform the patient in order to control leprosy in the community, or because leprosy needs to be eliminated. This is treating the patient as a means to a particular end. From this angle, any informed decision of the young man should be respected. But how has he come to his decision, and is it informed?

The principles of beneficence and non-maleficence identify a balance between the effort to help the person with leprosy and at the same time producing minimal harm. The traditional

Hippocratic moral obligation of medicine is to provide beneficence with non-maleficence: net medical benefit to patients with minimal harm. Here, treating the man is beneficent (and has social utility in reducing leprosy in the community) but telling him the diagnosis would seem to inflict psychological harm, at least, and be against his wishes. The principle of justice refers to the fair distribution of society's burdens and benefits, and is perhaps least relevant of the principles to this case.

In the control of leprosy, a balance is needed between moral concern for the individual with the disease, and concern for the community in which the disease may spread. For public health practitioners there is a constant tension between the rights of the individual and the rights of the population. But these rights need to be balanced with correlative duties. For example, if the community has established a system for identifying a person with leprosy, then the community has a duty to ensure that individuals are treated with dignity, fairness, respect and compassion.

Context and stigma

Leprosy is now a disease that can be treated and cured, but it is stigmatized.[9] It is surrounded by myth, by fear, and by isolation. So, as more is discovered and understood about the condition, it would appear correspondingly important to engage communities in a process of discussion and education about leprosy, with the overarching goal of reducing the stigma surrounding it. In each community, however, there is a different understanding of leprosy, different educational information, and different perspectives on how to control the disease with the minimum of harm to the patient.

With this in mind, it becomes clear that the approach of principlism, although helpful, is also somewhat simplistic. The relationship between the health care professional and the patient is central to the story and, of course, needs to be balanced, open, and to take account of the potential imbalance of power between the patient and health care worker. But this relationship itself must be placed, and understood, within the context of who the patient is, his or her knowledge of the disease, the stigma in the community, as well as the health care systems established to support that person during treatment and rehabilitation. If there are no support structures, then it may not be appropriate to simply tell the person that he or she has leprosy.

Ethical considerations are relative to the context in which they appear. While there is no easy solution to the case provided, there can be little doubt about the efforts needed to reduce the stigma of leprosy, and to create an environment in which informing the patient becomes an acceptable moral norm.

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Editorial

DISTINGUISHING BETWEEN RELAPSE AND LATE REVERSAL REACTION IN MULTIDRUG (MDT)-TREATED BT LEPROSY

This issue contains a report by Shetty et al. *on the incidence of viable* Mycobacterium leprae *in lesions presenting with reversal reaction. Dr Michael Waters comments on some of the issues raised.*

The two great advances, which both occurred around 1960, and which presaged the dramatic increase in the understanding of leprosy and its treatment in the following 2 decades, were the development by Ridley and Jopling of their classification of leprosy according to immunity,[1,2] and the discovery by Shepard of limited multiplication of *M. leprae* in the mouse foot pad.[3] The latter was rapidly confirmed and energetically applied by Rees,[4] so that the first cases of proven dapsone resistance were reported by 1964.[5]

In those early days, and routinely still today, the Shepard school inoculated 5000 and the Rees school 10,000 leprosy bacilli into the mouse foot pad, but both reported harvests averaging around 1,000,000 bacilli after 6–8 months, with no subsequent increase in numbers once this plateau count had been reached. With further experience, it was realized that a minority of strains of *M. leprae* isolated from patients gave slightly higher yields of 5000–10,000,000, and another minority gave low yields of around 1-500,000 bacilli, and that these characteristics were maintained on passage (subculture) in normal mice. Rees and his colleagues[6] also found that, in immunodeficient mice, multiplication continued after 6 months, sometimes the inoculated footpad became swollen, and yields of up to 1,000,000,000 (10^9) bacilli could be obtained; systemic spread of leprosy bacilli also occurred. For these early experiments, biopsies were taken from untreated or relapsed lepromatous (LL and BL) patients as the source of bacilli. I remember that workers at the Leprosy Research Unit, Sungei Buloh, Malaysia sent a few biopsies from smear-positive borderline-tuberculoid (BT) patients, but the tissue yields of *M. leprae* were usually very low, or even negative by normal counting methods, and the mouse foot pads at harvest were often negative, so that no more fresh BT tissues were sent at that time for mouse inoculation. I do not recall that any serious study by mouse footpad inoculation of strains of *M. leprae* isolated from BT patients was subsequently undertaken, although individual BT patients were biopsied for mouse studies for a variety of reasons.

As experience with the mouse footpad model developed, however, experiments were set up involving the inoculation of very tiny numbers of viable bacilli, especially in three areas. First, both Shepard[7] and Rees[8] did so, even though they still gave standard-sized inocula,

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when they obtained serial biopsies from patients commencing chemotherapy, for after the start of treatment the proportion of viable drops, whether dramatically with rifampicin or more slowly with dapsone and clofazimine. Second, tiny total numbers were injected in Colston's elegant Proportional Bactericidal Test.[9] It was found, quite logically, that when very few viable bacilli were present in the inoculum, 'takes' (that is, proven multiplication of *M. leprae* at harvest) were patchy, involving only a few or only one foot pad(s) in a single group of mice, and that such multiplication was frequently not detected until 12 months after inoculation, due to the extra number of generations required for the bacilli to reach detectable and plateau numbers; therefore protocols required most groups of mice to be kept for 12 months. Third, in their work on microbial persistence, Rees and his colleagues inoculated suspensions from a variety of tissues taken from treated LL and BL patients into immunodeficient mice. Many of these suspensions were either 'negative' (that is, bacilli, if present, were below the limit of detection), or gave very low counts. Nevertheless, in our first study, made on 12 patients who had received 10–12 years treatment with dapsone monotherapy, we were able to isolate three strains which passaged to normal mice, and were shown to be fully sensitive to dapsone.[10] However, in other experiments, we obtained a number of patchy counts of around 100,000 bacilli at 10–12 months in immunodeficient mice, and some of these strains failed to passage to normal mice; the explanation is by no means obvious. In all these experiments, Rees meticulously cultured the suspensions, usually on Lowenstein–Jensen slopes, to rule out the possibility of contamination with saprophytic mycobacteria, as, for example, there is one species that can live in distilled water.

With this background in mind, let us now consider the important report by Shetty, Wakade and Antia in this issue. The authors remind us of the well-known difficulty of distinguishing between relapse and late reversal reaction in multidrug (MDT)-treated BT leprosy. The World Health Organization has suggested a trial course of corticosteroids in such 'relapses', on the assumption that therapeutic steroids will suppress a reversal reaction and prevent or ameliorate any associated nerve damage, whereas the treatment would only partially and temporarily suppress a reaction due to viable bacteria (and the latter would continue to multiply during this period of steroid immunosuppression, so that acid fast bacteria might be more easily detected in smears, though hopefully any further clinical spread would be detected early). One assumes, for the authors do not give their precise protocol, that they were hoping to be able to distinguish between the two conditions by the detection in relapses of viable leprosy bacilli by mouse footpad inoculation, not present in reversal reactions due to an immunological response to antigen(s) from dead bacilli, (though it must be remembered that senior clinicians had seen bacterial relapse in dapsone and thiambutosine-treated BT-BL patients first present as reversal reaction), and to ascertain if steroids were of value in the differential diagnosis.

From a careful examination of their data, there is clear *prima facie* evidence of multiplication of leprosy bacilli in five experiments, namely those involving patients 1, 5, 10, 14 and 25. The results for patient 22 are less certain; although five of six foot pads gave counts of acid fast bacilli, the highest yield was only 140,000; was this a very low yielding strain, or were these counts analogous to the low counts obtained in persister studies, in which the strains of *M. leprae* did not passage? The patchy occasional counts obtained in some of the other experiments are of even more doubtful significance, especially those early positive counts at 6 or 8 months.

Of the five undoubted takes, four (1, 5, 10 and 25) had follow-up durations from release from MDT treatment (RFT) to relapse of 7, 9, 10 and 13 years, and from start of MDT to

relapse of 10, 11, 12 and 15 years. Only one patient, no. 14, who had received PB-MDT for 6 months, had had a short follow-up duration to relapse of 2.5 years. Three of the first four had received PB-MDT; only one (no. 25) had received MB-MDT, and he had had the longest duration from RFT to relapse of 13 years.

Surely, these data are not surprising, when one considers the size of the leprosy problem 20 years ago in the Mumbai (Bombay) region, though it would be helpful if the authors could give some estimate of the size of the tuberculoid or BT pool from which their special patients were obtained. Furthermore, it is known that relapses in BT leprosy can occur very late. I have myself briefly reported a patient who had a single, large anaesthetic lesion on his thigh at age 36, treated then so successfully with injections of hydnocarpus oil that he was not given dapsone when the drug became available, and who relapsed 40 years later, at the age of 76, with a new tuberculoid lesion on his face.[11]

In retrospect, it would have been very interesting to extend the authors' protocol, to include the passage of these five or six strains of *M. leprae* into fresh mice, both to confirm their viability, and more especially to study their drug sensitivities. For example, was strain no. 14 dapsone resistant, so that, in effect, he had received monotherapy with six doses of rifampicin? Were any of the five or six strains rifampicin resistant: Grosset and his colleagues have suggested that to select rifampicin resistant mutants, more than six, and possibly as many as 50 doses of rifampicin need to be administered;[12] all the authors' other positive strains had been subjected to at least 18 months of MDT, although one might hope that no rifampicin resistant mutants were present in the comparatively tiny bacterial load present in many BT patients. Furthermore, if any strain had been found to be rifampicin resistant, it would have been helpful to have the finding confirmed, either in another mouse footpad laboratory or by PCR, such collaborative tests being arranged, if necessary, through the World Health Organization. Outside confirmation is always helpful in chemotherapy, as the tragedy of the two reports of clofazimine resistance demonstrates;[13,14] one strain was never sent elsewhere, and the other was held up in transit. Such collaborative planning is best built into the original protocol, and if the authors extend their important studies, as many will hope, perhaps these suggestions may be included.

But already the authors have produced good evidence that viable leprosy bacilli can cause late relapse in BT leprosy, and that such relapses may be associated with reversal reactions. We shall welcome their further studies.

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SPECIAL REPORT

Reports from the workshop on the Neurologically Impaired Foot: 5–9 June 2000, Green Pastures Hospital, Pokhara, Nepal

Assessment and examination of the neurologically impaired foot

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Introduction

Foot impairments continue to be an important 'issue' in leprosy hospitals and community based programmes. Many persons both on treatment and released from (drug) treatment have, and often continue to have, foot impairments. Much time and money is spent on foot care that could have been prevented by early detection and more effective care, including teaching patient self-care. For most people in leprosy endemic countries, mobility is essential for socio-economic stability. Few can afford the loss of earnings that would result from the

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necessity to rest an ulcerated foot. Many are forced to accept the dilemma that if the foot is not rested there may be deterioration, giving rise to further impairments.

In the management of the neurologically impaired foot (NIF), it is important to know, and practise effective management that will benefit all persons with NIF. The areas of knowledge to be stressed are essentially related to the absence of pain perception, which frequently means that the patient neglects trauma and allows complications to develop. It is also important to address areas where knowledge is lacking or incomplete, for further study or research.

An International workshop was conducted at Green Pastures Hospital, Pokhara, Nepal (5–9th June 2000) to review and discuss issues relevant to the NIF. Participants consisted of small but broad-based group of health professionals, with experience in problems associated with NIF. Experience was primarily in leprosy but the issues raised are transferable to NIF from any aetiology, e.g. diabetes, trauma or hereditary motor sensory neuropathy. Those attending included reconstructive and plastic surgeons, physiotherapists and podiatrists. There are many important aspects related to the NIF. Expertise and skills from different disciplines are required to care for the foot at risk. This document is an attempt to give an overview of the 'state of the art' aspects of the care of the NIF.

The aims of the workshop were four-fold:

1. To clarify terminology.
2. To discuss and summarize relevant issues relating to NIF.
3. To present management updates.
4. To indicate areas for further research.

This is not a 'how to' document. This report does not attempt to be a comprehensive guide to management of problems associated with NIF. People that have no previous experience in the care and management of NIF are advised to undergo an in-service training or follow a formal course.

The recommendations are by consensus agreement and may not be the specific views of all the individuals present.

Terminology

INTRODUCTION

The terminology and dimensions of the International Classification of Functioning and Disability (ICIDH-2) were adopted as a guide to the discussions in the workshop and the writing of this report.[20]

DISCUSSION

The terms neuropathic foot and Charcot foot were found to be confusing in their meaning and application. These terms were defined for this report, with the hope that in others adopting these terms, uniformity in terminology will facilitate communication and research. The term neurologically impaired foot (see below) was coined to draw together a number of historically used terms in an attempt to clarify this terminology. It is hoped this term will be

accepted to achieve uniformity of language and thereby facilitate communication, between researchers and workers in this field.

Definitions

a. Neurologically impaired foot (NIF)
A neurologically impaired foot, is a foot with any degree of impairment of motor, sensory and/or autonomic, function. In leprosy varying degrees of impairment of all three types of nerve fibre are common. The primary impairment is the direct result of the nerve damage and examples of these include paresis and paralysis, sensory impairments such as the inability to feel pain, hypersensitivity and/or dry skin. The term neurologically impaired lower limb (NILL) may be used depending on the context.

b. Neuropathic foot
We suggest that for this paper, the term 'neuropathic foot' should be reserved for the foot which has impairment secondary to nerve impairments (e.g. ulcers, deformity, bone disorganization) as a result of primary impairments or damage to nerves. In other words, the neuropathic foot is the foot that is neurologically impaired and has developed secondary impairments or damage.

c. Neuropathic bone disorganization (NBD)
The term 'Charcot' joint/foot should preferably not be used to describe the many impairments that may occur in neuropathic bones in people affected by leprosy.

Use of the eponym 'Charcot' and the term neurarthropathy should be avoided on the following grounds:

1. What Charcot described as a neuro-arthropathic joint was a grossly deformed, unstable, hydroarthrotic joint the severity of which is rarely seen in leprosy, unless grossly neglected.
2. The diagnosis 'Charcot joint' often carries with it (in leprosy, but especially in diabetic foot care), the connotation that the foot/condition is untreatable, that nothing worthwhile can be done to treat the problem.
3. All feet with destructive bone changes tend to be labelled as Charcot joints. However, many lesions on radiograph, at least initially, do not involve the joints but are isolated to bones, e.g. fractures.[21]
4. Charcot joint is a misnomer, as in neuropathies from any cause the initial lesion is usually seen in bones (stress fracture) and the joint is secondarily involved. The term Charcot foot may be more applicable to a grossly deformed foot as an end result of healed bones/disintegrated joints. It is suggested that the acronym NBD should be used: neuropathic bone disorganization (or deformity). This is relevant for various stages of neuropathic involvement from any aetiology.

NBD can be defined as: sign(s) and symptom(s) of skeletal disorganization in combination with primary neurological impairment(s).

NBD is a disorganization of bone that may impair function. It is usually the result of trauma, which, because of reduced pain perception, is often neglected, so that continued use prevents healing. Resultant inflammation causes osteopenia, weakening the bones leading

to fracture, further deformity and/or disintegration with continued use. The first signs are local heat and swelling. If an affected limb is adequately rested and protected the bone lesions will heal in the position in which they are immobilized.

d. Protective sensation
The foot (as tested on the plantar surface) has definite loss of protective *touch* sensation, when at 2 or more locations on the sole of the foot (excluding the heel) a 10 g filament is not felt, or if on any one site firm pressure with the ball point pen (or heaviest filament, thick red) is not felt.[13]

Following discussion, the word *touch* has been added to what normally is referred to as protective sensation only.

Some patients, especially in diabetes and leprosy, appear to have intact touch sensation but decreased pain modalities. These patients may be at greater risk of developing NBD. It needs to be recognized that nerves are infected early in leprosy and it should be accepted that every leprosy patient already has some degree of neurological deficit at diagnosis, even if not clinically detectable. All clinical tests of sensation will help us understand how much nerve function impairment is present, and enable us to chart improvement, or otherwise, but apparently negative clinical tests may not always indicate absence of neural deficit.

e. Preventative rehabilitative surgery (PRS)
The term preventative rehabilitative surgery (PRS) is defined as surgery that is aimed at the prevention and correction of primary and secondary impairments due to nerve function loss or due to the disease itself (loss of eyebrows, nose deformity etc.).

Pedal biomechanics

INTRODUCTION

The role of pedal biomechanics and the affect of abnormal gait on the NIF foot are poorly understood. However, this remains a key area, both in the understanding of ulcer development and in the development of appropriate orthoses and shoes in the treatment and prevention of ulcers.[3,9]

DISCUSSION

Due to common congenital and developmental factors up to 85% of people have feet which do not function according to the ideal kinematic pattern.[5] Such abnormalities do not cause gross aberrations in gait patterns but result in moderate repetitive stress. In the non-compromised foot, this may not present as a serious problem because the integrity of the foot is maintained by safety information relating to current conditions of the substratum. Sensory feedback (at sub-threshold level) will cause the body to compensate for factors that cause excessive stress of the foot. If the sensory modalities are lost, due to neurological changes, the body will be unable to respond to such stresses and tissue integrity will be compromised.

A key factor influencing the integrity of the forefoot is the action of the subtalar joint. If the subtalar joint is forced to pronate aphasically, to compensate for an extrinsic abnormality, the effects include destabilization of the talo-navicular joint leading to

incompetence of the first ray and the plantar fascia. A further effect can be that motion around the first MTPJ is impeded due to functional hallux limitus. The consequence for the foot thus compromised include an uneven distribution of force leading to foci of high pressure under the second or third metatarsal heads, and shearing stress under the first metatarsal head. Excessive stress beneath the proximal phalanx of the hallux may lead to ulceration.[1]

When the subtalar joint is supinated aphasically, the effects include excessive rigidity of the foot. An abnormal plantar flexion of the first ray and a compromised anterior talofibular ligament are common secondary effects. The consequences for the foot thus compromised include foci of pressure beneath the forth or fifth metatarsal heads and in some cases high pressure beneath the first metatarsal head. 'Ankle' sprains may lead to chronic instability of the foot. There are also common forefoot aberrations from the ideal (e.g. forefoot varus, forefoot equinus) which will compromise the integrity of the plantar soft tissues.

MANAGEMENT RECOMMENDATIONS

Any person presenting with an anaesthetic foot due to posterior tibial nerve impairment and or motor loss due to lateral popliteal nerve impairment should undergo a basic biomechanical examination of the foot. Ideally the foot should be examined:[4,6]

i) In a *non-weight bearing* position to assess alignment between forefoot and the rear foot. This is done with the subtalar joint in neutral position.
ii) *Weight bearing* in stance to assess whether there is an inverted or everted hind foot. These impairments will result in compensations more distal in the foot during stance and push-off resulting in increased pressures at specific sites.
iii) *During gait*,[2,3] (and unpublished data).

The outcome should be used to decide whether podiatric orthoses might be used to maximize foot function, and prevent skin breakdown or ulceration. Where the foot is compromised by ulceration, an orthosis may be indicated as a therapeutic option.[2]

Gait analysis after tibialis posterior transfer (TPT) surgery for foot-drop correction should be extended to ascertain the extent and timing of subtalar pronation. In normal gait tibialis posterior acts to restrain excessive pronation. Removal of this mechanism may cause the subtalar joint to pronate without restraint. Excessive subtalar pronation may compromise the integrity of the talo-navicular joint and the forefoot.

Where it is deemed that the foot is at risk, due to excessive pronation, an orthotic intervention may be used to compensate for the loss of the posterior tibial restraining mechanism.

AREAS FOR RESEARCH

- To what extent does the subtalar joint hyperpronate following TPT and does it have significant clinical effects?
- Establish the level of inter- and intra-observer reliability of subtalar joint alignment assessment.
- Assess the effect of foot orthoses on force/pressure related parameters.

- A longitudinal prospective study on the effects of foot biomechanics as a cause of ulceration.
- Assess the acceptance and compliance of the wearing of prescribed footwear.

Assessment and recording

INTRODUCTION

The need for standard registration and recording forms was identified. This form should include level of impairment and ulcer classification/grading.

DISCUSSION

Registration form

Modification of the form as developed by the Dutch Neuropathic Foot Society, designed primarily to be used in people with diabetics, is potentially useful in the management of feet of leprosy affected persons. Such a form will facilitate communication between projects and may be very useful for research purposes. In projects in which only leprosy affected persons are seen, the section on location-deformity could be simplified by leaving out the sections on pulsation's which refer to persons who may have foot ulcers due to diabetes or other causes. With such a form, it is possible to code location, presence and type of ulcer, and presence of foot deformity, which may be related to the site and aetiology of the ulcer.

Hot spots

There is evidence that 'hot spots' can be reliably assessed by experienced health workers.[16] There is also evidence that areas of increased temperature can be reliably identified by persons affected by leprosy (Faber and 't Velt, personal communication). A hot spot is an area of localized heat and swelling when compared with adjacent tissues. In the absence of pain, hot spots serve as a reliable warning that there is internal pathology for which the patient needs treatment. A hot spot should be considered to indicate a bone lesion until proved otherwise.

Nerve function status

This should be part of a foot status registration form. In most leprosy programmes there will usually be a separate nerve function status (VMT-ST) form which can be referred to/consulted for information regarding the sensory and motor status of the foot (see below).

Nerve function impairment

a. *Motor function.* There is as yet no test that has proven reliability for grading the strength of the intrinsic muscles of the foot (posterior tibial nerve). Srinivasan suggests three different tests for the intrinsic muscles of the foot.[19] Other tests have also been used, e.g. fanning of the toes and gripping a piece of paper between the first and second toe (adduction).

One test that seems promising, in the sense that its strength can possibly be reliably

graded on a three-point scale, is abduction of the great toe. Voluntary abduction of the great toe is often not possible but contraction of the muscles can be 'triggered'.

The person rests their lateral calf on the thigh (hip, knee flexed, with the foot not resting on the thigh). The person is then asked to abduct the great toe. This movement is guided/triggered by giving some resistance in the direction of the movement that is required. The muscle belly of abductor hallucis can be clearly palpated (often seen contracting) when the muscle is functioning.

Standard VMT of all muscles below the knee should be checked and recorded at diagnosis and regularly thereafter, as a routine method of documenting changes in neural function.[10,11,15]

b. *Sensation.* Loss of protective touch sensation is a risk factor (not a cause) for plantar ulceration. Several studies have shown that the ability to feel a 10 g filament corresponds with the threshold for protective (touch) sensation.[13,18]

Research indicates that fewer than 10 sites can possibly be used to evaluate and monitor sensation of the sole of the foot without compromising sensitivity/specificity of the test.[12] With implementation of 'site reduction' for this nerve, sites for sural nerve and lateral popliteal nerve could be included still reducing total assessment time.[7,17] It should be taken into account whether the study looks into site reduction and/or filament reduction for screening purposes (loss of protective sensation) or if the purpose is for evaluating and monitoring function in sensory status.[15]

c. *Vibration, pain and thermal sensory modality.* At the time of writing this report, the ILEP supported INFIR (ILEP Nerve Function and Immunology of Reaction cohort study) is underway. This is a multi-centre study in which different nerve function assessment techniques are being used and compared for their sensitivity in the diagnosis, and responsiveness in the monitoring of nerve function impairment (NFI). Vibration and thermal sense perception are included. This study will show if vibrometry, thermal testing and electroneurophysiological testing is of additional benefit in the diagnosis and monitoring of NFI. In the testing of diabetic patients it has been shown that altered vibrations sensitivity is an indicator of risk of ulceration. However, results need to be considered in light of age and other factors. Often it is better to do a few tests fully and correctly than many tests that are incomplete and often meaningless and time consuming.

MANAGEMENT RECOMMENDATIONS

In a standard foot screen, besides general information, e.g. birth date, residence, leprosy status, screening should include the items shown in Table 1. It is recommended that the foot risk classification as proposed by Birke is part of a foot registration form.[8]

The type of (recommended) footwear and justification for its use should also be an essential item on a foot registration form.

It is recommended, when feasible/practical, to include assessment of sensation of the dorsum of the foot (lateral popliteal nerve) and lateral border of the foot (sural nerve) to evaluate and monitor sensory function of these nerves.

Table 1. Items for standard foot screen

	Basic	Detail
1. Nerve function status of the foot	VMT (3 grades)	Extrinsics; 6 grades Intrinsics (see text)
	ST (ballpoint pen/single filament)	More filaments and/or locations other tests Other nerves (e.g. sural, lateral popliteal)
2. Footwear	Y	Y
3. Marking impairments on foot diagram (cracks, claw toes, absorption etc.)	Y	Y
4. Risk categories of foot	N	Y
5. Localization of ulcer	Descriptive	Coded/graded as on the form/ulcer measured
6. Structural deformities	Y	Y
7. Biomechanical examination (functional impairments)	N	Y

Y = yes, N = no.

AREAS FOR RESEARCH

- It remains to be studied if, and to what extent, ulcer classification and deformity categories on a modified Dutch form are useful in the management of feet in leprosy endemic countries. Do categories need to be modified?
- Studies are needed, and other instruments may have to be developed, to be able to assess the impact of foot impairments on the degree of limitation of normal activities.
- Studies are needed that look into the reliability of the various tests that are/can be used for assessing the motor function of the posterior tibial nerve.
- Further research is needed to determine which filament to use (or what other tests should be performed regularly) and preferred sites, to detect early sensory loss. What are the sensitivity, specificity (validity) and reliability of each test, in the diagnosis of early nerve function loss, versus loss of protective sensation?
- Studies are needed to determine the relevance of sensory testing for sural nerve and lateral popliteal nerves.
- It needs to be determined to what extent proprioception/joint position awareness could be reliably assessed. Which joint(s)/movement(s) should be tested?
- It remains to be studied if, and to what extent, other sensory modalities (pain, temperature) can be affected in the presence of normal touch sensation.
- To what extent thresholds for definite diminished touch sensation (early loss) and loss of definitive touch sensation (protective) differ between the different parts of the foot (e.g. toes versus heel).

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SPECIAL REPORT

Complications and management of the neurologically impaired foot

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Ulcer aetiology and non-surgical management

INTRODUCTION

There tends to be a commonly held belief in health education and Prevention of Impairment and Disability (POID) teaching, that health professionals, as the 'experts', need only to inform those with leprosy related impairments how to take care of themselves and the responsibility is passed on. It was recognized during the meeting that often, attitudes and behaviour of staff need to change when 'empowering' persons with impairments or activity limitations due to leprosy or nerve function impairments, for their own self-care. These changes include an understanding of adult learning and working alongside those people with impairments to bring about permanent changes in behaviour.

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DISCUSSION

Ulcer aetiology

Risk factors in the aetiology of plantar ulceration include:[9]

- Loss of protective sensation
- Paralysis of intrinsic and extrinsic muscles (Srinivasan, 1964)
- Structural hyper/hypomobility
- Functional impairments
- Lifestyle
- Inadequate footwear
- Alteration of normal autonomic function resulting in anhidrotic skin. The consequent loss of elasticity compromises the skin, which may crack and fissure. Callosities become excessively dry and hard thereby creating a cause of localized high pressure
- Direct trauma or accidental trauma, e.g. treading on a tack, or impacting with excessive force
- Vascular and nutritional changes[2]

Restricted hallux dorsiflexion

Hallux limitus may be a risk factor in the aetiology of ulceration of the great toe. At least 60 degrees of hallux dorsiflexion is required for efficient propulsion. In order to affect adequate hallux dorsiflexion the 1st metatarsal must be stabilized in a plantar flexed position. If the 1st metatarsal is not adequately stabilized it may dorsiflex in response to ground reaction force during propulsion. The instability of the 1st metatarsal may result in an impingement of the proximal phalanx of the hallux against the head of the 1st metatarsal, thereby restricting hallux dorsiflexion. The demand for adequate dorsiflexion is met by forcing dorsiflexion at the IPJ of the hallux. A consequence is that a high focus of force is concentrated beneath the IPJ causing soft tissue breakdown. The effect of this problem is best reduced by addressing the causative factor rather than the effect. Hallux limitus is a common secondary effect of a foot that demonstrates aphasic subtalar pronation. This problem, when addressed by the timely use of an insole orthosis can be alleviated. An established osseous abnormality that has resulted from a hallux limitus is best addressed by the use of a curved 'roll over' sole.[1] Alternatively, the impairment can be surgically addressed.

Footwear

Properly fitting footwear (shoes with a closed upper or sandals with a heel strap) is essential for the prevention of plantar ulceration. Where necessary, modifications can be made to address abnormalities. Modifications should be made inside the shoe at the foot/shoe interface and not outside the shoe except where a rocker sole is required. Moulded shoes have very little effect and are known to be stigmatizing. A simple MCR protective inlay may be as effective as a moulded shoe.[7,8]

In the first instance, modified footwear should be used. However there is a place to 'make the foot fit the shoe rather than the shoe fit the foot'. This may have benefit in areas of the world where:

a) only locally made shoes are available;

b) wearing of special shoes is markedly stigmatizing or results in poor compliance;
c) adequate surgical facilities are available.

Corrective arthrodesis should be reserved for patients with severely deformed feet, or where ulceration has not been controlled with simple MCR and local shoes (with or without orthoses).

In patients with recurrent ulceration and failed conservative treatment, a corrective osteotomy or trimming of bony prominence can be performed. An additional soft tissue procedure, e.g. fascio cutaneous island flap, may be required.[3]

Orthotic devices

Subtle congenital and developmental impairments can place the insensate foot at further risk of plantar ulceration. It has been shown that certain orthotic devices designed to address these factors will facilitate healing and prevent re-ulceration. It is essential that where orthotic devices can be supplied, both the 'prescriber' and the appliance maker should understand the function of the 'ideal' foot because the objective of orthotic therapy is to assist the foot to function as close to the ideal as possible. Basic biomechanical examination and appliance manufacture training is essential if it is planned to establish a foot orthotic service. Patients need to realize that such orthotic appliances need to be worn at all times. If more than one pair of shoes is owned, appliances should be fitted to all shoes.

Soaking

To maintain the integrity of the skin of insensate feet, soaking and oiling is essential. The possible additional benefits of adding 'medication' to the water for soaking have not been shown. It was agreed at the meeting that *nothing needs to be added to the water* except the patient's feet, and that the oil, any oil, could be applied to wet feet. The soak rehydrates the dry skin and the oil retains the moisture. To oil without soaking is virtually a waste of oil! (NB some oil attracts rats).

Dressings/medication

In most instances, a clean dry dressing is sufficient to cover a plantar wound/ulcer. Saline may be used to clean wounds and in some instances (dry granulating wounds) saline dressings are indicated. Rest is essential. The rule should be not one step on an unprotected wounded sole.[6]

Generally speaking, no topical, systemic drugs or specialized dressing materials need to be used for wounds that are not infected. Only after radical ulcer debridement, when the integrity of unaffected tissue has been compromised, should an antiseptic such as betadine be used as prophylaxis (betadine is rapidly inactivated by body fluids).

Systemic antibiotics should be used only in cases of sepsis, lymphadenitis or lymphangitis.[9] In diabetes, the use of antibiotics is more commonly needed. There is some evidence that the wide variety of interactive dressings available in the West may accelerate wound healing, but the cost of such is usually prohibitive for use in leprosy programs/hospitals. There is evidence that these dressings without adequate rest will not increase healing rates, even in sensate limbs. Most neuropathic ulcers will heal with rest, simple dressings and without antibiotics. Using unnecessary medication or specialized dressings also has the distinct

disadvantage of creating dependency amongst those for whom self-care is the only sustainable long-term option.[11]

It should be noted that when surgery is indicated for drainage of pus or debridement of dead tissue, a period of time, usually 5–7 days, of immobilization with the limb in a splint and elevated in bed can localize the affected area and in many cases minimize the amount of debridement and hence tissue loss. If the pus collection is under pressure, then more urgent release may be indicated. Where possible, maintenance of anatomical structures should be pursued. It is preferable to return for a second debridement if needed rather than to take out tissues that do not really need to be removed.[5]

POID – self care (in addition to the above)

In view of the integration of leprosy services into general health services, and the existence/development of community based rehabilitation (CBR) programmes, the development of self-care/support groups should be encouraged. The functioning/dynamics of the groups should be the responsibility of the group itself.

The start of groups can be initiated from an existing POID program (officer) and together with the group members a 'curriculum' can be planned. The POID/officer/consultant will only have a facilitating role.

Where feasible and practical, self-care/support groups should consist of people with different impairments, activity limitations, and needs.[4] People should be encouraged to do their own dressings at home to avoid hospitalization for minor lesions.

Training institutions and referral centres should be encouraged to develop self-care units. In these units, clients will be responsible for their own wound care (soaking/dressing), cooking, maintenance of quarters, gardening etc.

Do not leave POID self care until patients are ready for discharge. From day 1 of attending clinic or admission, start to teach the patient to 'soak scrape oil' (SSO) then dress and fully rest. Then (s)he will really learn how, and will be more likely to continue at home.[10]

MANAGEMENT RECOMMENDATIONS

Moulded insoles should only be used for a rigid deformed foot, and if used they should also be supplied with a rigid sole.

Ulcers should be cleaned with water or saline only. Where surrounding tissue is at risk, an antiseptic such as diluted betadine solution or a protective cream, such as zinc may be indicated. Antibiotics are only indicated where there is evidence of systemic infection, e.g. fever or lymphadenopathy, and are not a substitute for appropriate surgical debridement.

Self-care support groups can be very effective in the prevention and treatment of uncomplicated plantar ulcers in the community. These groups should be self-sustaining with input from outside facilitators only when required.

When practical/acceptable, total contact casts (TCC) or plaster of Paris moulded double rocker shoes (MDRS) should be applied to facilitate the healing of plantar ulcers.[11,20,22]

AREAS FOR RESEARCH

Further research is needed to determine the relative role of loss of protective sensation,

intrinsic paralysis and structural and functional impairments in the aetiology of plantar ulceration.

A prospective trial of saline versus other additional wound solutions for soaking or dressing needs to be made. This should include local agents and solutions, easily available in local markets.[9]

Studies are needed to find out which patients benefit most (at what time) and for which reasons from self-care/self support groups. Which disciplines/professionals can be of help in changing attitudes and behaviour and how is this best done?

Surgical management of motor loss

INTRODUCTION

The correction of foot drop and claw toes by surgical means is well established.[15,16] However, certain points of the procedures and their long-term results remain unknown.

DISCUSSION

Surgical correction

Tibialis posterior transfer (TPT) remains the operation of choice, for dynamic correction of foot drop in leprosy.[12] There is no consensus regarding the route of the transferred tendon [interosseus (IO) versus circumtibial (CT)], or the site of insertion. Secondly, whether open or closed tendon Achilles lengthening (TAL) is required. There are 'indications' that the interosseus route may be preferred, but this has not been shown in a controlled study. However, it may result in a long-term better balanced foot with less inversion deformity.[14]

The important outcome measures are resting angle and active dorsi-flexion angle in swing through phase, and at heel strike. The aim of TPT is the restoration of normal gait. This is a more significant indicator than resting angles or range of motion, although these are all interrelated. Also important is the possible postoperative complication of inversion deformity.

Little is known about the effect of biomechanical changes, especially following changes to hind foot pronation following TPT.

Surgery for the flail foot

In exceptional cases when all the muscles below the knee are paralysed but the ankle passive range of motion is near normal, it is practical to tenodese the anterior tibial muscles and lengthen the Achilles tendon to provide a basically normal gait without evidence of foot drop.

Footdrop spring

A modified foot-drop strap is a good alternative for those who cannot/will not have foot drop surgery. This orthosis is worn on the distal lower leg only. The lining of the cuff should be of MCR and care should be taken that the distal rim of the cuff has many 2-cm deep incisions at

1-cm intervals. This will prevent undue pressure on the dorsum of the foot. The modified orthosis can be worn under trousers.[10]

Compliance with this orthosis seems to be much higher than with the conventional below knee toe-raising spring[18] or the above knee foot drop strap/spring which, when worn, is often not worn correctly (Lehman, personal communication).

Management of early foot drop by the use of steroids, a rest splint at night and a toe-raising spring by day, can result in recovery in a large proportion of patients who when recently diagnosed may develop a permanent foot drop. All patients with a foot drop should be encouraged to wear a toe raising spring or other orthotic device, from diagnosis until surgery is available.[17]

Claw toe deformity

Mobile claw toes can be corrected by transfer of FDL to EDL (Girdlestone procedure). Fixed claw toes can be treated by resection of proximal phalanx and tenotomies, or PIPJ arthrodesis. In the presence of a reversed metatarsal arch, Srinivasan recommends proximal shift of EDL to metatarsal neck (sometimes combined with fusion of PIP joint) and shaving off the plantar side of the head of the metatarsals. This he sees as an alternative to the often-advocated metatarsal head resections. These procedures can be done at the time of the TPT operation or delayed if indicated.

MANAGEMENT RECOMMENDATIONS

Tendo-Achilles lengthening (open or closed) is recommended in all foot-drop corrections. During surgery aim to achieve 15–20 degrees of dorsi-flexion when the knee is out of its fixation splint.[13]

Tendon insertion should be in tendon(s) and/or Y ligament, not in the bone or periosteum. Resting angle following tendon suture should ideally be 15–20 degrees above right angle. Immobilization should be in maximum dorsi-flexion 15–20 degrees above right angle. A drop of 10–15 degrees within the first year post-surgery is common.[13]

It is important to analyse gait at postoperative follow-up and to see this as a key measure of successful outcome. A basic biomechanical examination is also necessary. The adjunctive use of in-shoe sole orthotic devices where indicated is also recommended.

AREAS FOR RESEARCH

It is recommended that a controlled study be conducted in which the two techniques of tibialis posterior tendon transfer (IO and CT) are compared with respect to outcome.

A comparative trial of short-term and long-term results of closed versus open-tendo-Achilles lengthening is needed.

A standard gait and biomechanics assessment following tibialis posterior tendon transfer (TPT) needs to be developed for comparison of techniques used in surgery and comparing long-term outcomes.

To what extent is there phasic conversion of tibialis posterior muscle activity following transfer? Is TPT still useful as a static-supporting sling when phasic conversion is often not expected as in the elderly?

What functional/structural consequences are there for the subtalar joint following tibialis posterior removal and should this be compensated for? Are additional orthoses required?

Does TPT change the frequency of metatarsal head and/or lateral boarder ulceration, or simply increase the number of heel ulcers?

Neuropathic bone disintegration (NBD)

INTRODUCTION

Neuropathic bone disintegration is a poorly recognized condition (especially in early presentation), with inadequately understood pathophysiology, often leading to delayed and incomplete treatment with serious long-term sequelae. The following discussion and recommendations attempt to clarify these areas and give clear guidelines for treatment.

The classic presentation of inflammation in any body part is heat, swelling, redness and pain. When in a neurologically impaired limb pain perception is compromised we must learn to assess the other features.[23] If there are no other signs of infection, it is unlikely that painless local heat and swelling are due to infection. If in doubt, rest the limb and observe. With rest, any inflammation will localize and if heat and swelling (a hot spot/area) subsides in a few days and does not return when walking is resumed, it was unlikely to be a serious bone lesion or infection. Hence it was probably a relatively minor traumatic lesion, or minor infection usually requiring no further treatment. If doubts of severe infection such as osteomyelitis remain, treat as NBD but give antibiotics as well and keep in a total contact cast (TCC) for 6 weeks or longer and then review with new radiographs (2 and 6 weeks). An X-ray initially may not show any abnormal signs, but if there is NBD it may be recognized by about 6 weeks on X-ray due to the degree of osteopenia that has developed. X-ray signs of osteomyelitis may be evident from 2 weeks.

DISCUSSION

NBD should be suspected in every patient with a painless hot swollen foot or area of the foot that settles rapidly on full rest but returns as soon as walking resumes. The first sign of impending NBD is usually a 'hot spot/area' that is a localized area of heat usually with some swelling, when contrasted to the adjacent tissues or contralateral limbs, which indicates tissue pathology. Trained health workers and patients or their relatives can reliably assess these hot spots. These hot spots or local areas of inflammation occur from a variety of causes, but most commonly a bone lesion with active bone metabolism in response to some insult or injury. It is critical to detect these early, adequately immobilize and rest the foot, and allow sufficient time for bone healing and consolidation. If adequately treated, all will heal, but it is recognized that in a neurologically impaired foot (NIF) with NBD the bone healing may take 2–3 times longer for the bone lesion compared to normal. The sequence of treatment is three-fold: a period of
non-weight bearing or immobilization (to reduce swelling for cast application), followed by a period of protected weight bearing in a TCC and then trial walking.

If a patient presents with a warm swollen foot, routine examination ought to eliminate osteomyelitis. Elevated white cell count, positive microbiological cultures, lymphadenitis and lymphangitis on examination, and systemic symptoms are suggestive of osteomyelitis.

Tagged white cell scans or bone scans are more conclusive. If these are positive, antibiotics should be started and the initial treatment includes rest with the foot splinted and elevated till the swelling decreases. If the swelling decreases within a few days and returns with walking, it is probably NBD, not osteomyelitis. Do not try to diagnose NBD by biopsy, as this may introduce infection and there is a great possibility that a biopsy will not remove a piece of definitely affected bone, which may be only a very small area. The biopsy will damage the bone and this encourages osteopenia around the biopsy area, which predisposes to NBD.

Bone can be involved in different ways in leprosy:

a) Direct infiltration by bacilli due to a deep septic ulcer may produce periostitis or osteomyelitis. Osteomyelitis results in osteopenia that predisposes to destruction and deformity.
b) Due to neurological deficit and repetitive stress that may lead to (stress or march) fractures.
c) Direct trauma leading to a fracture, (microscopic or macroscopic), especially when there is chronic hyperaemia, which can itself cause osteopenia predisposing to fractures.
d) Direct parasitization by leprosy bacilli causes cysts but rarely produces disintegration.

Predisposing factors for NBD are reduced pain perception in bones or joints and osteoporosis or osteopenia. Osteoporosis or osteopenia can occur due to prolonged immobilization in a cast (6 weeks in a cast can predispose to stress fractures on commencing unlimited walking), hyperaemia from any cause, e.g. infection, chronic lepra reaction, steroid therapy, age, calcium deficiency, diet and other causes.

It should be noted that although immobilization may further induce osteoporosis, immobilization is the treatment of choice in NBD. Immobilization is essential until disintegration has halted, and the broken bones have healed and are strong enough to stand the stress of usage. A radiographic examination cannot show definitely if the bone is fully healed.[27] The most useful way of testing is by use the of the limb in trial walking.

MANAGEMENT RECOMMENDATIONS

When hot spots/areas are present, the foot should be treated as if NBD is present, until proven otherwise.

If a disintegrating bone lesion is suspected but cannot be confirmed by an X-ray and the foot is hot (swollen), it should be treated as if NBD is present. Rest and elevate, use a TCC and review in 6–8 weeks by radiograph and/or trial walking.[19,22]

If an X-ray can be made, it should be taken. Weight-bearing lateral (full length of foot) and AP-oblique X-rays will give the most information.[28]

The minimum length of time for immobilization in a total contact walking cast is 3 months for confirmed or minimal lesions. Advanced cases may require 9–12 months of immobilization.[24,29]

Recommended times of immobilization are:

a) Talo-calcaneal disintegration: 3–4 months.
b) Ankle disintegration: 6 months.
c) Mid-tarsal disintegration: 9–12 months.
d) Gross disorganization and or decalcification requires 12–15 months but should heal eventually.

With associated septic neuropathic disintegration, weight bearing is not allowed until the sepsis is controlled and all swelling subsided.

Weight bearing in a TCC can be achieved by different means. A full length wooden foot piece or rocker is best to ensure the arch is supported as needed.[20] An overshoe is useful in making walking easier, especially if both feet are affected. A rubber heel also plays a role. The use of a Bohler iron is advised, when there is destruction of the ankle or ulceration over the peak of a boat-shaped foot. Terrain and climate are variable, and probably will determine which device is best used for an individual to facilitate walking.[27]

Trial walking should be started after immobilization in a TCC. Trial walking starts for 3–5 min, with the use of suitable footwear, and then the patient rests for 2 h. If there is no heat or swelling at the end of 2 h, the patient can walk again for 3–5 min. Duration and frequency of trial walks can be slowly increased, until the patient can walk for 30 min (without heat and swelling of the foot), including stairs and rough terrain. These periods of walking can occur 3–4 times per day, once the patient learns to monitor themselves. If the foot becomes hot and swollen, even after reducing the duration of walking, it should be rested or again immobilized in a TCC. Trial walking could also be resumed when the foot is cool but with reduced frequency and duration.[25,29] Recurrence of persistent heat and swelling suggests that there is still residual internal, pathology, not yet fully healed. Repeated recurrence of heat and swelling is best managed by a further 6–12 weeks in a TCC, followed again by trial walking. Patients with chronic cardiac or renal problems may well have repeatedly swollen ankles but there will be no heat if the swelling is unrelated to bone lesions.

A bi-valved modified total contact cast instead of a fixed TCC can sometimes be useful when expertise is available to make them, but not as a routine for active bone disorganization, disintegration or fractures.[21,29]

When end stage (consolidation, no further disintegration) is reached, the patient may require a moulded boot, and/or ankle brace or patellar weight-bearing device orthosis.[21] However, in suitable patients in whom there has been adequate immobilization and trial walking has been completed successfully, no further device but a suitable shoe is required. If the disorganized foot can be moulded into a functional shape before the cast is applied, or can be surgically reconstructed, it should be possible for the patient to live the rest of his life in 'normal' shoes with a resilient insole. Following this, a carefully planned procedure with internal fixation of all osteotomies and prolonged immobilization can be made.

Corrective arthrodesis in a patient with NBD can be successful. It is indicated in a patient where without significant correction, the foot remains ulcer prone and non-functional. Surgery needs to be delayed at least 3 months, in a TCC from the time of presentation with acute disintegration, until initial heat and swelling has settled. This allows the active disintegration phase to settle and improves the likelihood of fusion. Following this, a carefully planned procedure with internal fixation of all osteotomies and prolonged immobilization, can be made. If the reconstruction is adequate and immobilization long enough the patient should not require special footwear afterwards. In some cultural groups, the use of prolonged casting is not acceptable and alternate methods of treatment may be used.[26]

AREAS FOR RESEARCH

- Does NBD occur in the presence of normal touch thresholds?
- To what extent is the lack of or diminished proprioception a risk factor in the development

of a disintegrating bone/joint lesion? Does diminished/lack of propriocepsis and/or temperature sense occur independently from diminished/lack of protective sensation?
- Is there a delay in fusion if corrective arthrodesis is performed during healing in active NBD? Should surgery be delayed until complete healing has occurred? A study is needed, comparing the fusion rate, between corrective arthrodesis of deformed feet secondary to acute NBD performed at 3 months after the onset of treatment, versus the time for complete healing and consolidation without surgery.
- What footwear or orthotic devices are required for the ongoing management and protection of feet following healing after acute NBD? A comparison between the use of a fixed ankle brace verses footwear alone after treatment of NBD could also be performed.

Surgical management of the anatomically deformed foot

INTRODUCTION

Surgical procedures (soft tissue reconstruction, e.g. grafts and flaps, arthrodesis or amputations) may be required when the foot is structurally badly deformed. These procedures may also be indicated when there is little viable tissue for weight bearing, or the foot is very unstable.

DISCUSSION

Soft tissue reconstruction

The place of conservative treatment and/or a cast in the treatment of ulcers is well established. However, this often leads to healing with marked scarring. Pressure over bony prominences can lead to recurrent ulceration requiring hospital admission. A variety of soft tissue procedures from simple lateral calcaneal paring to more complex island vascular pedicle flaps can be used to improve the quality of soft tissue cover. Any soft tissue coverage needs to deal with the underlying bony prominences, usually with simple bone trimming. These flaps leave better quality weight bearing skin and in conjunction with good self care and appropriate footwear can prevent re-ulceration, prolonged foot survival and decrease in amputation rate. However, these do require expert surgical techniques and adequate facilities.

Arthrodesis

An arthrodesis or corrective osteotomy can be performed in the insensate foot, but immobilization needs to be 2–3 times longer than in the normal sensate foot to achieve consolidation.[29,30]

The aims of corrective arthrodesis are that the patient can become ulcer free, have a socially acceptable foot and walk in appropriate footwear, with, often, increased and appropriate weight-bearing surface.[33]

Amputations

Amputations are a last resort for the badly deformed and re-ulcerating foot. In confirmed

cases of malignancy, amputation is usually indicated although there may be a place for local excision and soft tissue reconstruction.

The options for amputation include below knee (BK), tibio-calcaneal (T-C) (Pirigoff or Boyds) fusion,[34] ankle dis-articulation (Symes), and a variety of forefoot amputations. Factors that should determine the level of amputation are the patients' preference, underlying pathology, and the skills of the prosthetist. A Symes amputation may require a patellar weight-bearing prosthesis. Re-ulceration is not uncommon. A T-C fusion does not usually require a prosthesis, because it provides a more stable heel pad. In a T-C fusion the leg is almost normal in length, initial immobilization in a walking plaster cast is required for the first 3 months, and then the patient is able to walk without additional support. Following a Symes amputation, they require additional support with crutches for the first 6 months. Both Symes and T-C fusion have a better long-term prognosis if the heel is still sensate. The ideal length for a BK stump for prosthetic fitting is 10–16 cm. Some surgeons leave a longer stump and in all cases the prosthetist should be consulted on the ideal length of stump for prosthesis.[31]

MANAGEMENT RECOMMENDATIONS

Recurrent/chronic foot ulcers can be managed with soft tissue reconstruction where indicated and surgical expertise is available.[3]

Corrective arthrodesis should be strongly considered as an alternative to radical amputation.

Often, racial/cultural variations in the acceptability of BK amputations (BKA) exist. It must be clearly seen that it is the patient's right to chose and the medical professional responsibility to enable that choice to be an informed decision, but seen as an option of last resort.

In many areas, the supply of orthotics and prosthetics is difficult, and repair and replacement in remote areas is impossible. The provision of a T-C fusion will allow the patient to use basketball boots that lace above the ankle so they do not need a prosthesis. Hence, it may well be the amputation of choice when the heel pad is good, and results have shown high patient acceptability.[32]

AREAS FOR RESEARCH

- A prospective comparative study of the long-term outcome of radical amputation procedures for squamous cell carcinoma of foot (BKA) versus local excision and reconstruction.
- A study looking at the long-term follow-up of a variety of soft tissue reconstruction and flaps for ulcers of the sole of the foot. This study would attempt to give guidelines for recommended treatment options; their indications and the skill base need for these procedures.
- Develop training programmes and ongoing supervision for surgeons involved in procedures requiring soft tissue reconstruction in feet.

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An intensive self care training programme reduces admissions for the treatment of plantar ulcers

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Summary This paper describes, in detail, an intensive 14 day Self Care Training Programme that is conducted at Lalgadh Leprosy Services Centre in Nepal. An evaluation of the programme was undertaken in which hospital admission for infected plantar ulceration was the outcome measure. It was found that those who had undertaken the programme were less likely to have been admitted for hospital treatment in a 3-month follow-up period (χ^2 = 5·1, P = 0·02). An odds ratio of 1:1·8 (95% CI = 0·15–0·01) was also calculated. This paper presents an overview of the issues related to impairment, a description of the Self Care Training Programme, an analysis of the evaluation results and a discussion of the findings.

Introduction

It was Waxler's[1] contention that the tragedy of leprosy has little to do with the bacillus *per se*. In her opinion the patient's experience of the disease is profoundly affected by the social beliefs and expectations of the society in which the individual participates. For similar reasons, Valencia[2] cautioned that conventional models should not be used to assess the affects of leprosy, because it is not simply a physiological dysfunction: it is a complex psycho-social phenomenon with profound consequences for the affected person, his/her family and the community. According to Parsonian theory, it is in the course of social interaction that values and rules are constructed. He suggested that in all societies there are pre-existing cultural systems of ideas that are used to construct and modify the labels that direct societal behaviour towards those affected by disease.[3]

In the Indian subcontinent, the term *'Illness of Untouchability'*, as coined by Berreman,[4] is apt because it resonates with cultural meaning that helps to define the social effects of the disease. In his study of leprosy in the Chingleput district of Tamil Nadu, Rao[5] stated that, *'The general perception of leprosy within a community is confined to conditions associated with deformity'*. (This observation is repeated with emphasis throughout the literature.) Rao demonstrated that 81% of respondents in his survey did not recognize that hypopigmented patches or nodules were a symptom of leprosy. However, 89.6% of the same group associated leprosy with deformity or ulceration.

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Clearly the chronic nature of the disease, with its potential to inflict gross deformity, is traumatic primarily for the patient but also for his/her social environment. In the Indian subcontinent there is no strong concept of 'self'. It is the corporate need of the body of the family (closely followed by the need of the community) that is significant rather than the individual in isolation. Accordingly, when individuals are denied a role in the family and community their lives are perceived as essentially meaningless.[6,7]

For the reasons suggested above, it is essential that every effort is made to limit the extent to which secondary complications of leprosy extend to cause deformity, limitation of activity and restrictions in social participation. The principal agent in the control of his or her illness will be the affected person him/herself, which is why every effort must be made to empower the affected person adequately for the challenge. Self care has been the mainstay of prevention of disability for many years. Watson[8] has vigorously promoted the concept and has striven to encourage programmes to emphasize the necessity for teaching pragmatic methods of self care.

Ethiraj *et al.*[9] conducted a study of the effects of community based self care. They compared the affects of community education on one group of people affected by leprosy, and individualized input from trained field staff on another group. They reported that self care behaviour in both groups was better than a control group that received no input. Mathew *et al.*[10] reported that the prevalence of simple ulcers was reduced by 50% after intervention from trained field staff who taught home based self care procedures to people impaired by leprosy.

Kemper *et al.*[11] conducted a comprehensive review of self care interventions. Their focus was primarily on self-initiated responses to symptoms of acute illness and as such, their results were not appropriate for comparison with this study. However, they did review papers that focussed on self care education programmes (primarily educated communities in America) and in summarizing their findings they concluded that, generally, research had indicated the effectiveness of self care education as a means to reduce health care utilization. They also emphasized the consistent reporting that self care had not resulted in dangerous practices.

The Lalgadh Self Care Training Centre

A recent innovation at the Lalgadh Leprosy Services Centre (a project of Nepal Leprosy Trust) has been the development of the Self Care Training Centre (SCTC). The centre provides an environment, separate from the medical services, which focuses on prevention of impairment and disability and enhancement of social participation. This is accomplished through imparting effective self care strategies and social skills within a quasi-educational rather than a medical environment.

GENERAL AIMS

The responsibility for the management/prevention of impairment and disability and the empowerment of the individual to act within his/her society will be shifted from the health professional to the individual. In this way, dependency effects will be reduced and individual control will be strengthened.

SPECIFIC AIMS

1. To establish and reinforce essential measures of self care for people impaired by leprosy.
2. To enable people impaired by leprosy to self monitor changes in nerve function.
3. To enable people impaired by leprosy to recognize other indications for self referral (e.g. renewal of footwear and appliances).
4. To enable people impaired by leprosy to conduct activities of daily living effectively and independently.
5. To empower people psychologically for the challenges of living in a potentially hostile environment.

HUMAN RESOURCES

The SCTC Facilitator has responsibility for demonstration and advice on all self care activities related to the prevention/management of impairments. He identifies special needs and directs accordingly. He also leads group discussions, undertakes an active role in training of social skills and counselling. He is aided by two full-time assistants.

A major emphasis in the self care programme is safe methods of daily labour. For this purpose land has been made available within the Lalgadh Hospital compound for the purpose of small scale farming activities. A sound understanding of the common causes of secondary impairments enables the facilitator to advise trainees in methods to adapt implements and/or adjust methods of work. Buffalo husbandry is also conducted. Apart from the obvious focus on self care the farming activities also evoke familiarity. This has been a deliberate move to enable people to associate self care procedures with normal activities of daily living.

The initial assessment of people who fulfil the criteria for entry to the SCTC is conducted in the Outpatients Department at Lalgadh Hospital and through other contact situations. The ward manager of the Inpatients Department (IPD) also identifies people who fulfil the criteria for transfer to the SCTC. Candidates from the IPD are recommended to the facilitator who assesses the person and decides whether he or she should be offered a place in the SCTC.

MATERIAL RESOURCES

Dormitories

A purpose built Centre was constructed. The Centre can accommodate 24 persons in two dormitories (one female and one male). The Centre also comprises a multipurpose room for teaching/discussion purposes. To reduce the semblance of a hospital, the interior decoration of the accommodation dormitories was painted with a wash that resembles the colour of village dwellings. Simple bamboo and webbing beds have been provided.

Kitchen

A building was converted to resemble a typical village kitchen (dung and clay walls and floors, clay ovens and storage facilities). Village cooking equipment and other utensils have been provided. Cooking is undertaken by participants, thereby providing an essential learning environment, particularly for women.

SCTC PARTICIPANTS

Entry criteria

Those considered for participation in the programme are:

1. People newly diagnosed with leprosy who present with anaesthetic hands and/or feet and/or muscle paresis or paralysis.
2. People being treated or released from treatment presenting with early signs of deformity or ulceration.
3. People under 55 years of age (unless they show an unusual degree of motivation).
4. People at high risk of type 1 or type 2 reaction.
5. People for whom prednisolone treatment has been prescribed.
6. People showing signs of depression.

Particular effort is made to persuade women to participate because in the socio-cultural context of the study, women are traditionally discriminated against and are therefore considered by the authors to be more vulnerable. Where possible, spouses are also encouraged to enter the programme and to participate in it.

Participation

During a 14-day stay, trainees are expected to participate in an organized programme. The programme rotates continuously so that people enrolling at any stage in the 14-day programme will still benefit from the full programme (details of the programme are given in the Appendix).

On concluding the programme, participants are asked to complete a post-training assessment. On departure, they are presented with a certificate of participation and a gift which includes a small mirror, a comb and a 1 m^2 sheet of polythene (polythene sheeting is used to line holes made in the ground for foot soaking).

Materials and methods

STUDY GROUP

Subjects for the study group were obtained by analysing records from the SCTC. All trainees who had completed the 14-day intensive training programme between July 1998 and July 1999 were selected. A requirement was that all subjects met the inclusion criteria of the SCTC as previously outlined. The study group comprised 254 trainees (66 females and 188 males). The female to male ratio (1:2·8) closely reflected the ratio of registered cases at LLSC at that time (1:2·6). Mean age of the group was 35 years.

CONTROL GROUP

Hospital main files were checked for exclusion criteria for the control group, i.e. patients who had been transferred out, those who had been in the SCTC and defaulters. Remaining files were checked and all patients with impairments who would have been eligible for the SCTC but who did not enter the programme between July 1998 and July 1999 were selected. From these, 254 files (75 females and 179 males) were randomly selected to form the control group. The mean age of the group was 39 years.

FOOT IMPAIRMENTS

A further selection was then performed: all files were checked to determine the number of subjects with foot impairment in each group. In the study group, 192 subjects had foot impairment, whilst in the control group, 206 subjects had foot impairment. Further analysis was undertaken using data describing these sub-groups.

The outcome considered was whether or not subjects had been admitted for the treatment of complicated, infected ulceration within a period from July 1998 to October 1999. (Three months beyond the closing date for inclusion into the study was given to allow for possible hospitalization of people who had participated in the programme at the end of the review period.)

DATA ANALYSIS

Hypothesis

People who did not undergo training in the SCTC were more likely to have been admitted for hospital treatment of complicated infected ulcers than people who had undertaken the SCTC programme.

Null hypothesis

There will be no difference in the number of admissions for the treatment of complicated infected ulcers between people who had undertaken the SCTC programme and others who had not.

Results

No significant differences were found between the study and control group when compared on leprosy status and gender, however, a statistical difference was found between groups on age ($P = 0{\cdot}006$) (Tables 1, 2 and 3).

The number of subjects in the study group with foot impairments totalled 192 (76%), and of this group, 24 had been admitted to hospital for treatment of a complicated foot ulcer. In the control group, 206 (81%) of subjects had foot impairment, and of this group, 43 had been admitted to hospital for treatment of a complicated foot ulcer.

When compared on admissions, the groups were found to be significantly different

Table 1. Comparison between groups on leprosy status. There were no significant differences between groups

	Care after cure	Registered patients	Total
Study	71	121	192
Control	77	129	206
Total	148	250	398

Table 2. Comparison between groups on gender. There were no significant differences between groups

	Male	Female	Total
Study	141	51	192
Control	142	64	206
Total	283	115	398

(Table 4). However, because of the difference in age distributions among the groups the groups were further broken down and an age-wise comparison was made.

Only one person in the Control group under 21 years had been admitted and four people in the same age group from the Study group had been admitted. Further comparison therefore was restricted to those over the age of 20 years (Study group, n = 171, Control Group, n = 199).

With the difference between the Study and Control groups still being significant, we suggest that the findings were therefore not biased by the age differences between the two groups (Table 5).

ODDS RATIO (OR)

An OR of 1.8 (95% CI = 0·15–0·01) was calculated. This suggests that people with impaired feet who did not undergo training in the SCTC were nearly twice as likely to be admitted for treatment of a complicated ulcer than people who did participate in the programme.

On the evidence cited above, we reject the null hypothesis of no difference and suggest therefore that the SCTC programme at Lalgadh Leprosy Services Centre (LLSC) may have a significant effect in reducing admissions for the treatment of infected complicated ulcers among people with foot impairments.

Discussion

The prevention of plantar ulceration is not the only reason for including people in the self care training programme. We therefore accept that it is only a partial measure of efficacy. However, our contention is that the necessity to admit people for hospital treatment is partly an effect of the dominant causal and recovery belief system that influences an individual's

Table 3. Comparison between groups on age

	<21 years	>20 years	Total
Study	21	171	192
Control	7	199	206
Total	28	370	398

$\chi^2 = 7{\cdot}5$, $P = 0{\cdot}006$.

Table 4. Comparison between groups: hospital admissions for complicated plantar ulcers

	Yes	No	Total
Study	24	168	192
Control	43	163	206
Total	67	331	398

$\chi^2 = 4{\cdot}4$, $P = 0{\cdot}03$.

self care behaviour. We suggest that ulcer prevention indicates more than skill or knowledge; it also indicates attitude and self-esteem.[12]

Although established guidelines and recommendations[8] had been implemented at LLSC, it was found that almost 20% of all people who were registered with foot impairments were being admitted for the treatment of infected plantar ulceration (many of these will have multiple admissions). Apart from the scale of medical and technical interventions that this patient load demands, the dilemmas of dependency and dehabilitation are also recognized as problems. Although the follow-up period for this study was relatively short (3 months), it was demonstrated that of those who did participate in the SCTC programme only 12% were subsequently be admitted for treatment.

For demographic and resource reasons, it is unrealistic to aim at a clinician to client ratio that might be sufficient to ensure adequate control over the incidence of infected plantar ulceration. For this reason, the most significant agent to take responsibility for the prevention of secondary impairment is the client him/herself. The facilitation of essential skills and attitudes to accomplish this objective should therefore be given high priority. Care should be taken when setting such an objective not to be too ambitious. It should be accepted that not all who complete the programme will be motivated. Attitude is a very complex phenomenon that is affected by many variables.

The programme aims to bring impairment prevention and participatory skills to all aspects of the clients' lives. The potential benefits in terms of control, heightened self-esteem, and confidence that may result from the acquisition of knowledge and from affirmative interaction during the course has not been assessed. However, it is possible that the development of subsequent social skills may have a far more profound impact on the lives of those who complete the course than simply learning physical damage limitation skills.

The aims and objectives of the Self Care Training Centre being wide and varied have

Table 5. Comparison between groups: >20 years of age who had hospital admissions for complicated plantar ulcers

	Yes	No	Total
Study	22	149	171
Control	42	157	199
Total	64	306	370

$\chi^2 = 5{\cdot}1$, $P = 0{\cdot}02$.

stimulated a number of investigations that are currently in process. These studies are aimed to give further objective evidence to support or refute the hypothesis that the Self Care Training Programme enhances the quality of life of those participating in it. The effects of the programme on activity levels and social participation will hopefully also give insight into the association of impairment and ability. Sound science has established the validity of the Green Patures Activity Scale,[11] which has facilitated the collection of further relevant data. It would also be useful to conduct a gender analysis to ascertain the extent to which gender issues are affected by the programme.

In conclusion, the study has demonstrated that an intense period of self care training does appear to effect positive behaviour. The proportion of people admitted for treatment amongst those who underwent the SCTC Programme was significantly less than a control group. We recommend, therefore, that an intense period of training is an effective means by which clients can be enabled to take control over the effects of leprosy.

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Appendix

OBJECTIVES

1. On completion of the SCTC programme, participants will be:
   a) Aware of essential self care procedures for their specific impairments.

b) Able to identify and use appropriate materials and resources to effect adequate self care.
c) Able to discuss the implications of self neglect.

2. On completion of the SCTC programme, participants will be:
   a) Able to conduct and monitor basic sensory and voluntary muscle testing for hands and feet.
   b) Able to conduct a basic eye examination.
   c) Aware of indications for self referral for early neuritis.
   d) Discuss the implications of failing to report changes.
3. On completion of the SCTC programme, participants will be:
   a) Able to assess their footwear and hand or foot orthoses.
   b) Able to discuss the implications of wearing unsuitable footwear/appliances.
4. On completion of the SCTC programme, participants will be:
   a) Able to use assistive devices competently.
   b) Able to suggest/identify appropriate alternatives/replacements.
5. On completion of the SCTC programme, participants will have:
   a) A positive self image.
   b) A desire to return to their home environment.

14-DAY PROGRAMME

Sunday to Thursday

6 a.m. to 8 a.m.	Soaking, oiling and scraping of feet and hands
8 a.m. to 9 a.m.	Cooking activities and breakfast
9 a.m. to 10 a.m.	Exercises
10 a.m. to 11 a.m.	Group discussion (from Monday to Thursday, a different impairment related problem is discussed. On Sunday, social issues are discussed).
11 a.m. to 12 noon	A different health related topic is presented each day, e.g. nutrition, vomiting and diarrhoea, family planning, personal hygiene
12 p.m. to 1 p.m.	Lunch
1 p.m. to 2 p.m.	Basic literacy (the objective is to teach participants how to write their own name)
2 p.m. to 4 p.m.	Farming or domestic skills
4 p.m.	Review of day's activities

Every Friday a social programme is planned to enable participants to develop and express normal socio-cultural skills.

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Lagophthalmos surgery in leprosy: findings from a population-based survey in Korea

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Summary Lagophthalmos continues to be a serious problem in cured leprosy patients. We conducted a population-based survey of lagophthalmos surgical coverage (LSC), barriers to lagophthalmos surgery and outcome of lagophthalmos surgery in leprosy patients in South Korea. In our survey, there were 60 patients with lagophthalmos who had needed surgery (> 5 mm gap), 34 of whom had received surgery, resulting in a lagophthalmos surgery coverage of 57%. Among the 34 patients who had received lagophthalmos surgery, 18 needed further surgery. Among those who had never had surgery, none of the demographic indicators predicted surgical uptake; the primary reason given for failure to have surgery was lack of knowledge about it. Outcome of surgery (by eye) showed that 29% of eyes still had a gap of 5 mm or more. The frequency of symptoms (tearing, blurring of vision, pain, etc.) was high. Even in settings with a good eye care infrastructure, such as Korea, uptake of surgery can still be low and results may not be satisfactory to patients. There is a need for practical guidelines for leprosy control programmes in the areas of (a) patient recognition, (b) patient education, (c) monitoring the uptake of surgery, and (d) monitoring the outcome of surgery to ensure the best possible outcome.

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Introduction

We have recently demonstrated that lagophthalmos continues to be a serious problem among cured leprosy patients.[1] In Korean leprosy patients (all cured mycobacteriologically for over 12 years) the presence of lagophthalmos (even on gentle closure) was associated with a 7·5-fold risk of incident corneal keratitis compared to patients without lagophthalmos. In this population, although cataract was the leading cause of incident bilateral blindness (87%) and visual impairment (80%), corneal disease secondary to lagophthalmos was the second most frequent cause. By eye, corneal disease accounts for 19% of incident blindness (vision < 6/60) and 56% of incident visual impairment (vision < 6/18). Thus, corneal disease is responsible for a significant proportion of uniocular vision loss.

A survey of lagophthalmos surgical services reveals a wide variety of surgical procedures in use worldwide as well as varying indications for surgery.[2] There is considerable variability in the literature regarding outcome of surgical correction of lagophthalmos;[3–6] however, the findings are generally inconclusive due to small samples, inadequate follow-up, or methodological flaws. Information on surgical outcome is helpful for determining the benefits of surgical interventions as well as helping to revise surgical indicators and procedures.

There is no information in the literature documenting the lagophthalmos surgical coverage (that is, the proportion of lagophthalmos patients who have had surgery) among leprosy patients. Lagophthalmos surgical coverage should be one measure of the success of a leprosy control or blindness prevention programme. In measuring lagophthalmos surgical coverage it is important to determine why those who need surgery have not had it. These barriers can then be addressed to increase lagophthalmos surgical coverage.

In this study, we sought to determine the lagophthalmos surgical coverage, the barriers to use of lagophthalmos surgical services, and the outcome of lagophthalmos surgery.

Materials and methods

This study was undertaken in six leprosy resettlement villages in central South Korea. Leprosy is not a public health problem in Korea anymore; only 39 new leprosy cases were recognized in 1998. There are 18,800 patients who have been treated and released, about 36% of whom live in resettlement villages. The health care infrastructure of Korea is very well developed; government and non-government programmes provide free medical (including eye) care for all leprosy patients. A well-managed tertiary eye care programme is centred at the Catholic Skin Clinic and Hospital (CSCH) and leprosy patients from the resettlement villages under study as well as domicillary patients from surrounding countries have access to a well-trained ophthalmologist and plastic surgeon who have been providing surgery for lagophthalmos (primarily the lateral tarsal strip procedure) for the past 10 years.

In late 1988, standardized clinical examinations were undertaken on 501 (83%) of 605 patients among eight leprosy resettlement villages in the area. Findings from these investigations have been reported previously.[7–9] In the year following the examinations, the CSCH recruited an ophthalmologist to provide services for these patients. In May 1999 standardized eye examinations were repeated among the study population and the findings have been reported.[1] Methods for detection of ocular pathology have been described previously.[7–9] Briefly, visual acuity was taken (best eye presenting vision) using an illuminated tumbling E chart by a trained examiner. Clinical examinations were conducted

by two examiners (Dr Lee Ho-Sung and SL in 1988 and NCT and SL in 1999). Corneal sensation was determined by the reaction to a cotton wisp introduced from below. Blink pattern was measured by observing the patient while he/she was unaware of being examined; it was graded abnormal when there was more than 15 seconds between blinks or if the blink was incomplete. Lagophthalmos was defined as present in 'gentle closure' when a gap was detected when a patient closed his eyes gently, as in sleep and in 'forced closure' when a gap was detected when a patient closed his eyes tightly. The gap was measured using a millimetre ruler. Presence of corneal opacity, corneal ulcer, and keratitis was also recorded. Demographic information was obtained from patient charts. Data on one patient, who had lagophthalmos secondary to a burn, was not included.

Following the clinical examinations, interviews were conducted by graduate students at the Department of Sociology, Keimyung University among all lagophthalmos patients (operated or not) to determine the barriers to surgery and satisfaction with surgery.

Lagophthalmos surgical coverage (LSC) was defined by patient rather than by eye. All patients with 5 mm or greater lagophthalmos in gentle or forced closure (in one or both eyes) or history of lagophthalmos surgery comprised the denominator and all patients who had had surgery for the correction of lagophthalmos (regardless of current status of lids) comprised the numerator.

We divided patients into two groups (no surgery versus surgery) and used standard univariate analyses (Students' *t*-test for continuous variables and chi-square for dichotomous variables) to evaluate the factors associated with not having surgery. Odds ratios and 95% confidence intervals were calculated. Findings from in-depth interviews on barriers to acceptance of surgery were tabulated.

Finally, outcome of surgery was evaluated, by eye rather than by patient. Clinical criteria for outcome included presence of lagophthalmos (none, 1–4 mm gap, and 5+ mm gap), corneal conditions (cornea ulcer or scar), and vision. Information on symptoms (excess tearing, blurring of vision, pain, disfigurement, and foreign body sensation) was also recorded at the time of examination; analysis of symptoms was by patient.

Results

There were 60 patients (33 men and 27 women) who either had had lagophthalmos surgery or needed surgery (≥5 mm gap). The 60 patients can be broken down as follows: 16 patients had had successful lagophthalmos surgery (lid gap < 5 mm) and 44 patients needed surgery. Among the 44 patients needing surgery 18 (40·9%) patients had a history of surgery but needed more. Thus, among the 60 patients 34 (56·7%, 95% confidence interval: 44·2–69·2%) had undergone surgery in the past; 57·6% for men and 55·6% for women. The proportion of males needing additional correction (15/19 or 79%) outnumbered females needing additional correction (3/15 or 20%); there was no association with age or disease type. Just under half (47·7%) of the patients needing surgery had bilateral lagophthalmos.

None of the demographic factors was associated with a failure to receive lagophthalmos surgery (Table 1). Among the 26 patients who did not have surgery, in-depth interviews were conducted with 19 patients. The reasons given by patients with lagophthalmos for not having surgery were lack of knowledge of surgery ($n = 6$), cost and distance from village ($n = 4$), service of poor quality ($n = 4$), lagophthalmos not a problem ($n = 3$) and other reasons ($n = 2$). Only nine patients (47·4%) knew another person who had lagophthalmos surgery.

Table 1. Demographic and clinical factors associated with use of lagophthalmos surgical services

	Had lagophthalmos surgery ($n = 34$)	Did not have lagophthalmos surgery ($n = 26$)	Odds ratio (95% confidence interval)
	No. (%)	No.	
Age			
≥60 years	13 (52·0)	12	1·0
> 60 years	20 (60·6)	13	1·42 (0·44–4·64)
Gender			
Male	19 (57·6)	14	1·0
Female	15 (55·6)	12	0·92 (0·29–2·91)
Duration of leprosy			
≥40 years	9 (52·9)	8	1·0
40+ years	24 (58·5)	17	1·25 (0·35–4·53)
Type of leprosy			
MB	22 (59·5)	15	1·0
PB	12 (52·2)	11	0·74 (0·23–2·41)
Distance from hospital			
Near	22 (56·4)	17	1·0
Far	10 (55·6)	8	0·97 (0·27–3·44)

Among patients who had a history of surgery but needed more there was considerable resistance to additional surgery due to a perception that surgery did not give a good outcome.

The absence of preoperative information on these patients makes it impossible to assess whether the current findings (vision, corneal conditions) were present before surgery. Among the 34 patients with a history of surgery, in-depth interviews were conducted with 25 patients. Five patients (20%) would not recommend surgery to others because of a failure to improve vision and continual tearing. Overall, seven patients (28%) were not satisfied with surgery, five because their lagophthalmos recurred and two because vision worsened.

Table 2. Characteristics of eyes with a history of lagophthalmos surgery*

Clinical sign	No. (%)
Exposure of globe (on gentle closure)	
No exposure	9 (21·9)
1–4 mm	20 (48·8)
5+ mm	12 (29·3)
Exposure of globe (on forced closure)	
No exposure	14 (34·1)
1–4 mm	16 (39·0)
5+ mm	11 (26·8)
Ectropion	
None	12 (29·3)
1 mm	24 (58·5)
2–3 mm	5 (12·9)
Ectropion of puncta	
None	34 (82·9)
Present	7 (17·1)

*Information available on 41 patients.

Table 3. The contribution of time elapsed since surgery on the presence of clinical characteristics in patients with a history of lagophthalmos surgery

	Time elapsed since most recent surgery		
	< 10 years No. (%)	10+ years No.	OR (95% CI)
Lagophthalmos (on gentle closure)			
< 5 mm	20 (68·9)	9	1·11 (0·21–5·74)
> 5 mm gap	8 (66·7)	4	1·0
Lagophthalmos (on forced closure)			
< 5 mm	20 (66·7)	10	0·75 (0·12–4·23)
> 5 mm gap	8 (72·7)	3	1·0
Ectropion			
None	11 (91·7)	1	7·76 (0·81–182)*
Present	17 (60·7)	11	1·0
Ectropion of puncta			
None	24 (75·0)	8	3·0 (0·37–24·9)
Present	3 (50·0)	3	1·0
Symptoms reported			
Excess tearing			
Yes	21 (67·7)	10	1·05 (0·0–18·1)
No	2 (66·7)	1	1·0
Blurring of vision			
Yes	13 (68·4)	6	1·08 (0·20–5·79)
No	10 (66·7)	5	1·0
Pain			
Yes	12 (60·0)	8	0·41 (0·06–2·40)
No	11 (78·6)	3	1·0
Disfigurement			
Yes	8 (57·1)	6	0·44 (0·08–2·40)
No	15 (75·0)	5	1·0
Foreign body sensation			
Yes	12 (63·2)	7	0·62 (0·11–3·39)
No	11 (73·3)	4	1·0

* Fisher's exact 2-tailed $P < 0.05$.

Among 48 eyes which had undergone surgery, additional information on clinical conditions was available on 41 eyes, among which 12 (29·3%) had 5 mm or more of exposure of the globe on gentle closure (indicating the need for further surgery) (Table 2).

Among the patients who had had surgery, the frequency of symptoms reported was high; 91% reported excessive tearing, 56% reported blurring of vision, 59% reported pain, 41% reported disfigurement, and 56% reported foreign body sensation; these findings were generally not associated with duration since most recent surgery (Table 3). Ectropion was 7·7 times more common among patients who had surgery 10 or more years ago than among those who had surgery more recently.

Discussion

The prevalence of lagophthalmos in leprosy patients varies considerably among populations, primarily as a result of life expectancy, previous leprosy control efforts, and composition (leprosy type) of the population under study. None of the people in our study were new

leprosy patients or leprosy patients currently undergoing MDT. While lagophthalmos incidence in MDT appears to be quite low there are still a considerable number of lagophthalmos patients needing surgery.[2]

While there are no standard criteria for defining clinically significant lagophthalmos, we chose the definition of 5 mm or more gap on gentle closure[10] for this study. Further indications for surgery could include disfigurement and significant symptoms (e.g. excessive tearing or irritation), or a specialist's judgement that the cornea is endangered. In addition, duration of lagophthalmos needs to be considered in patient selection; patients with new onset (< 6 months) lagophthalmos require steroid treatment. Adoption of semi-standardized criteria for the selection of patients for surgical intervention is useful for health workers to identify patients for referral for surgery. This would also assist with monitoring lagophthalmos surgical coverage. In a recent ILEP report, it was noted that 91% of ILEP programmes report checking the lid for closure but that only 47% offer surgery.[11] Clearly, the gap between reconition of lagophthalmos in the field and interventions to manage lagophthalmos is problematic.

When surgery is available, standard assessment of clinical outcome is recommended. In Korea, where the quality of surgery is quite good, 29% of eyes still had 5+ mm lid gap. Presumably the ectropion, more common among patients who had surgery over 10 years ago, is a result of ageing and gradual laxity of the lid. Excess tearing was reported by almost all patients and was responsible for most of the dissatisfaction of patients. Further investigation of the best procedures, which may vary among individual patients, is indicated. However, it is unlikely that 100% success can ever be achieved.

The fact that almost one-third of patients were not aware of the possibility of surgery for lagophthalmos is surprising; this finding suggests the need for more intense education efforts to describe the surgical procedure, benefits and risks, and the need for follow-up. In addition, the poor satisfaction reported by patients with multiple surgeries indicates the need for more intensive education of patients at the time of surgery as well as during follow-up.

The findings in Korea represent settings with aged cured leprosy patients rather than settings with active MDT programmes. Nevertheless, our findings suggest a need for creating practical guidelines for leprosy control programmes in the areas of (a) patient recognition, (b) patient education, (c) monitoring of uptake of surgery, and (d) monitoring the outcome of surgery to ensure the best possible results.

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Capture-recapture method to assess the prevalence of disabled leprosy patients

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Summary The capture-recapture technique was applied in estimating the prevalence of disabled leprosy patients in four States in Northern Nigeria. A two-sample capture-recapture method, using data from hospital admissions during 1997 and 1998 in three leprosy referral hospitals, and from a sample survey on leprosy patients with disabilities in the clinics in 1999. In the sample, 1395 (ex) leprosy patients were found, 393 with a disability. Of these 393 patients, 47 had been admitted during 1997 and 1998 to one of three leprosy referral hospitals. In these hospitals, 151 individuals from the 24 study Local Government Areas (LGA) in four states of Northern Nigeria were admitted in 1997 and 1998. Using the Peterson estimator, we calculated the number of unknown disabled leprosy patients in the studied LGAs to be 1262 (95% confidence interval 991–1533). This was nearly four times greater than the field reported figure. The capture-recapture method can be applied in a leprosy care programme. Limitations of the method are the completeness of reporting after invitation in the field, as well as the probable biased sample of leprosy patients admitted to hospital. Our finding implies that relying on patients to report for prevention of disabilities and rehabilitation to the clinics, causes the real size of the problem to be underestimated by a factor of 3–4. We recommend the use of a special 'care' register for disabled leprosy patients to better address their needs for prevention of disabilities and rehabilitation.

Introduction

In any prevention of disabilities and rehabilitation programme for leprosy one would like to know the effective coverage of the services. The number of patients in need of care within a

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given country is often unknown. Care for disabled leprosy patients depends largely on the existence of a prevention of disabilities programme and of functioning leprosy referral hospitals with services for physical rehabilitation. Initially, leprosy control programmes originated from these leprosy hospitals. It is therefore unsurpising that traditionally, most leprosy patients would find their way to such hospitals, often circumventing the referral system of leprosy control programmes.

Even in the literature there are few reliable estimates of the disability burden from leprosy. However, the number of leprosy patients in need of care can be estimated by sampling or modelling.

1. Population surveys of persons with disabilities due to leprosy, like Rapid Village Surveys or Leprosy Elimination Campaigns, and extrapolation of the findings to the whole population.
2. Inviting all leprosy patients with a disability in the catchment area of a clinic to come forward, after selecting clinics in a sample survey.
3. Demographic modeling,[1] based on age and sex specific incidence of impairments and disabilities, estimated life expectancy, and the dynamics of impairments and disabilities, both during and after treatment.
4. Capture-recapture techniques among leprosy patients with disabilities, registered at the referral hospital and recaptured during a field survey.

In this paper we discuss the application of methods 2 and 4.

Capture-recapture[a] methods were originally developed in wildlife conservation,[2] and later applied in a variety of fields, notably in demography, epidemiology, criminology and service schemes for people with chronic conditions, such as cancer patients,[3,4] homeless, alcoholics and other substance abusers,[5-8] HIV positive people,[9,10] and other marginalized and covert populations,[11] including disabled persons.[12] Many authors consider the method very useful in counting people in public health studies,[13,14] the technique being quick, easy and cheap. Others have offered criticism, specifically concerning the issue of validation of the calculations[15] and problems with perfect matching,[16] the more so in developing countries.

The principle of capture-recapture is to use two or more overlapping sources of information. It measures prevalence of individuals based on two or more samples, whereby individuals are marked during the first sample and recaptured during one or more successive samples.

The ratio of individuals registered (marked) in both samples (m) and patients registered in the first sample (M), equals the ratio of all individuals in the second sample (n) and the total unknown number (N). This relationship is also known as the Peterson estimator,[17] namely $m/M = n/N$ (Figure 1).

We conducted a sample survey of disabled leprosy patients reporting to clinics, proportional to the number of patients registered for MDT. This survey was carried out in six Local Government Areas (LGA) in each of four states of Northern Nigeria, as part of a needs assessment study. We included a capture-recapture method to assess its utility in estimating the prevalence of patients in need of care. We then compared this with the results of the sample survey, to assess patient compliance when invited to report to the clinic.

Over the past 7 years, the average leprosy case detection in Nigeria has been 7120 new

[a] The term capture-recapture may appear stigmatizing when used for humans. However, it is the commonly used term. Some authors use marking-recatpure, or dual record matching instead.

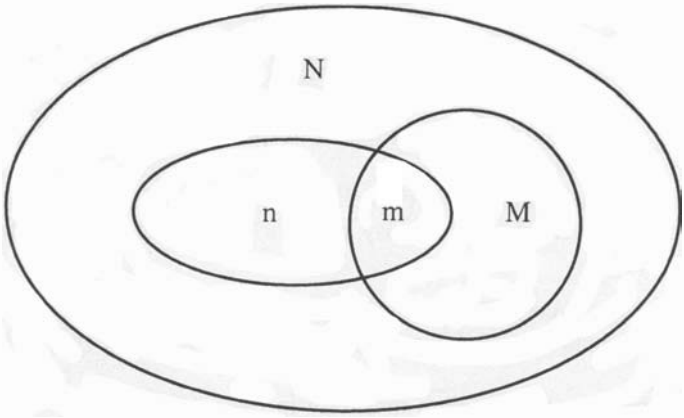


Figure 1. Graphical representation of the relationship between captured (n) and recaptured (M) populations, their overlap (m), and the estimated total (N) population.

cases per year, with on average 16% of these having a disability grade 2 according to the WHO disability scale.

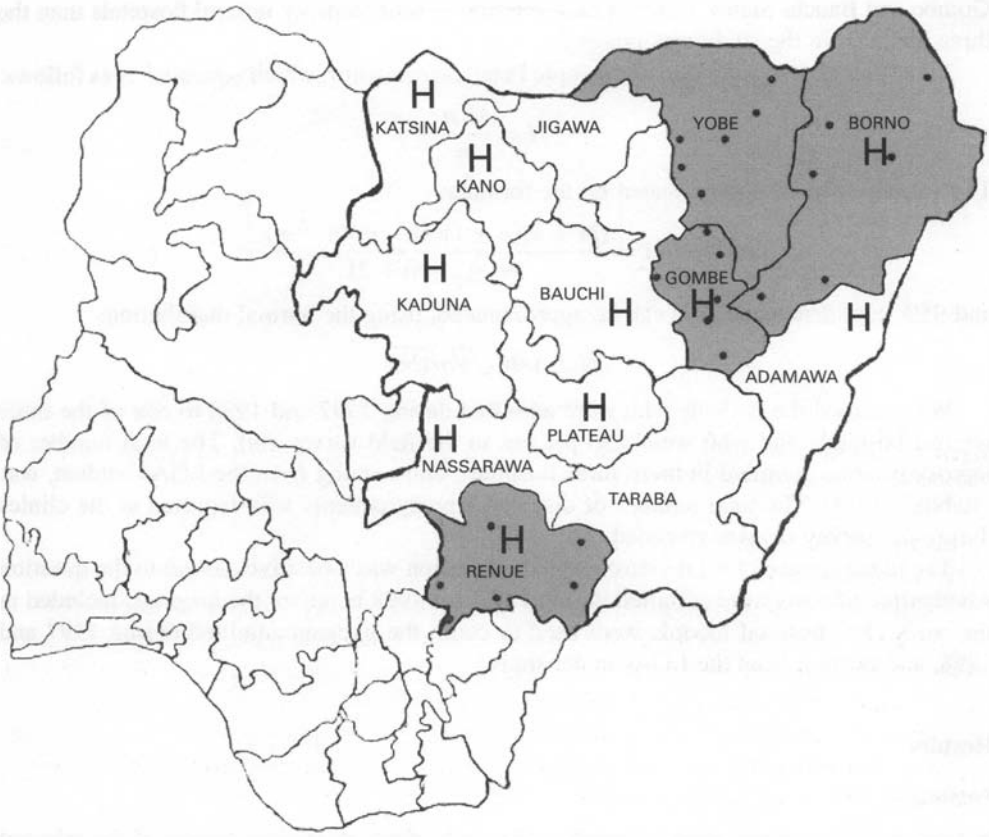
In Northern Nigeria, there are 13 states supported by the Netherlands Leprosy Relief (NLR), 10 of which are serviced by a leprosy referral hospital (Figure 2). In these 13 states alone, over 55% of all new leprosy patients in Nigeria are diagnosed, while 37% (46,550,000 out of 126,375,000) of the population lives in these states.

Leprosy control programmes, including services for the prevention of disabilities and physical rehabilitation, have been functioning already for some time. Admission of leprosy patients in other than the leprosy referral hospitals rarely occurs.

Materials and methods

We selected four states out of the 13 NLR-supported states in Northern Nigeria: Benue, Borno, Gombe and Yobe States. These states were selected on operational grounds, such as capacity for research and non-involvement of the programme staff in other concurrent important activities. In 1998, there were 1469 leprosy patients registered for MDT. In each of these four states we selected six LGAs according to a sampling scheme, proportionate to size of registered leprosy patients, as was used for Rapid Village Surveys of leprosy in Thailand.[18] We listed the LGAs with the number of patients registered for MDT, and divided the total number of patients by six to determine the sampling interval. We selected the first LGA with a dice and then continued to select the other five LGAs with the calculated interval. In the clinics of selected LGAs, there were 809 patients registered for MDT in 1998. Therefore, the total weighted sampling fraction was 0·551.

This study was part of an 'Assessment of Impairments and Needs' study to answer the questions of how many patients have disabilities, what kind and degree of disabilities they have, and what their needs for intervention are. For this purpose an instrument was developed and field tested, consisting of a questionnaire and a standardized checklist for recording results of physical examination. The questioning and physical examination was carried out by the State Leprosy Supervisor, under supervision of the State Leprosy Control Officer and/or the Prevention of Disability Supervisor.



Key:

Named states:	states supported by Netherlands Leprosy Relief.
Grayed states:	states selected for study.
H:	leprosy referral hospitals.
Dots:	capitals of Local Government Area in which study was performed.

Figure 2. Map of Nigeria.

During monthly routine clinic days, announcements were made to all currently attending patients and ex-patients, requesting them, and any other ex-leprosy patients they knew, to attend the next monthly clinic. The community was further sensitized and mobilized through health staff, community leaders and leprosy chiefs.

At the next monthly clinic, all persons who came forward with a disability due to leprosy were interviewed and examined according to the standardized questionnaire and checklist. The WHO definition and grading of disability for leprosy was used.

We collected data from the three leprosy referral hospitals of the four states, namely Molai Hospital for Borno and Yobe States, Mkar Hospital for Benue and Bayara Hospital for

Gombe and Bauchi States. Referral or admission to other leprosy referral hospitals than the three included in the study was ignored.

In the analysis, we used the two sample Peterson estimator, which equation[b] is as follows:

$$N = \frac{M^* n}{m}$$

The variance can be approximated by the formula:

$$Var(N) = \frac{(M+1)(n+1)(M-m)(n-m)}{(m+1)^2(m+2)}$$

and 95% confidence intervals can be approximated, using the normal distribution:

$$N \pm 1{\cdot}96\sqrt{Var(N)}$$

We recorded the patients who were admitted during 1997 and 1998 to one of the three referral hospitals and who were also present in the field survey (m). The total number of leprosy patients admitted in these three hospitals, and coming from the LGAs studied, was established (M). The total number of disabled leprosy patients who reported at the clinics during the survey (n) was recorded.

The identifier used for previous hospital admission was a positive answer to the question whether the patients were admitted during 1997 and 1998 in any of the hospitals included in the study. The hospital records were used to count the patients admitted during 1997 and 1998, and coming from the LGAs under study.

Results

SAMPLE

A total of 1395 patients were included in the study, from all leprosy clinics of the selected 24 LGAs in four states. All were interviewed and physically examined. Of these, 393 had a disability or were experiencing leprosy reactions. Out of these patients, 81 (21%) were still on MDT. On average, there were 15·7 disabled persons per LGA, with a standard error of 3·7.

With these data we could calculate the total number of person with disabilities due to leprosy in the four states by dividing 393 with the sampling fraction 0·551, resulting in 714, with a 95% confidence interval of 384–1043.

CAPTURE-RECAPTURE METHOD

Of the 393 patients (n) found with disabilities, 47 (m) could be identified as also having been admitted during 1997 and 1998 to one of the three leprosy referral hospitals studied. In these hospitals, we identified 151 individuals (M) who were admitted in 1997 and 1998, coming from the 24 study LGAs.

Applying the Peterson estimator, we calculated the estimated number of disabled leprosy patients in the LGAs of the four states to be 1262, with a 95% confidence interval from 991 to 1533 (Table 1).

[b] Other authors recommend the use of Seber's adjustment to the unbiased Peterson estimator,[4] which is suitable for smaller sample sizes and smaller overlapping registrations, and corrects for the fact that there is no replacement after recapture. Its equation is $N = \frac{(M+1)^*(n+1)}{m+1}$

Table 1. Presence of patients with disability, admitted during 1997 and 1998, from hospital records and from field sample records, in the studied LGAs of four states combined. Between brackets are the parameters used in the formula. The findings from the study are presented in boldface

Presence of patients with disability		Field data		
		Yes	No	Total
Hospital data	Yes	47 (m)	104	151 (M)
	No	346	765	1111
	Total	393 (n)	869	1262 (N)

Table 2. Peterson's estimator and 95% confidence intervals of the number of leprosy patients with disabilities in the studied LGAs, stratified per state

State	m	M	n	N	95% CI	
Benue State	17	48	120	338	229	447
Borno State	13	61	102	478	289	667
Gombe State	12	23	44	84	59	109
Yobe State	5	19	127	482	223	741
Total	47	151	393	1382		

Stratification according to state yielded a similar overall estimate of 1382, although, of course, with relatively larger confidence intervals (Table 2).

We compared the age distribution of these categories with the total number of patients with disabilities found in the field, broken down to patients still on MDT at the time of the study and patients released from treatment (RFT) sometime in the past (Table 3). We did not further analyse patients without disabilities.

In addition, the disability grading, according to the summation of the WHO scores for eyes, hands and feet, both right and left, (also called the EHF score, with a range from 0 till 12) differed between these categories. 67% (54 out of 81) of patients still on MDT had an EHF score of 4 or less, against 44% (138 out of 312) of RFT patients.

Additional analysis of the data shows that the difference in age distribution of the 151 admitted patients, as compared to the 47 recaptured, was statistically significant (Table 4).

Table 3. Age groups of MDT and RFT (released from treatment) patients with disabilities found in the field

Age group	MDT patients with disabilities	%	RFT patients with disabilities	%
0–14 years	2	2	0	
15–44 years	44	54	86	28
> 45 years	35	43	217	69
Unkown	0		9	3
Total	81	100	312	100

Table 4. Age groups of admitted and recaptured patients with disabilities

Age group	Admitted patients	%	Re-captured patients	%
0–14 years	5	3	1	2
15–44 years	82	54	14	30
> 45 years	60	40	32	68
Unknown	4	3	0	
Total	151	100	47	100

Chi square for trend = 6·468, $P = 0{\cdot}011$.

We recaptured the older of the previously admitted patients. The records of the admitted patients did not allow a classification and analysis according to the EHF score.

In all, 223 (57%) out of the 393 individuals found with a disability had, at the time of examination and in the opinion of the examiner, one or more indications for admission to a leprosy referral hospital. The indications included severe leprosy reaction (20 times), and/or septic or reconstructive surgery (201 times), and/or need for amputation and/or prosthesis (17 times).

Discussion

The estimate of 1262 (95% confidence interval 991–1533) patients by applying the capture-recapture technique is a factor 3–4 higher than the 393 disabled leprosy patients found in the survey. The large unknown or hidden population of disabled leprosy patients could partly be explained by the fact that the registration of disabled patients at the clinic was a one-time event, rather than an ongoing process. Presently, no care register exists for disabled leprosy patients in Nigeria.

ASSUMPTIONS UNDERLYING THE TECHNIQUE

As a quick and cheap method, the two-sample capture-recapture method is an appropriate tool to gain an impression of the number of persons missed by the health care system. The confidence interval tends to be larger when the number of overlapping registrations (m) are smaller. In our study the confidence interval of the grouped analysis did not exceed 22% of the calculated value.

However, the technique is rough and biased. Underlying assumptions and possible violations include the following:

- The *population is closed* (geographically and demographically), so that the size is constant. Disabled leprosy patients, like all human beings, tend to have complex and hidden patterns of behaviour, sometimes favouring distant instead of nearby hospitals. Although it is possible that some may have traveled to other states, this number is likely to be very small, given the huge distances to other leprosy referral hospitals and the existence of similar services nearby. Likewise, some patients may have died or migrated, and others may have developed new disabilities. However, this effect is likely to be

minimal, given the expected small numbers of new disabled patients or death/resettlement over a period of 2 years.

- *Homogeneity of the population*, meaning that all individuals have the same chance of being hospitalized (captured or marked) and of subsequently being included in the sample (recaptured). The invitation procedure may have caused bias in the number and type of patients with disabilities who came forward. For instance, the inclusion of patients from leprosy settlements could present such a problem. These patients may have different demands for care, than disabled persons living in a normal village. There was one leprosy settlement under the 24 LGAs of this study, contributing only 22 disabled leprosy patients. Patients with previous admission could have a different health seeking behaviour and expectation of cure or care. A way to deal with heterogeneity would be stratified analysis. Stratification by state in our study revealed similar results to those without stratification (Table 2). Stratification by age revealed differences in the patients admitted and recaptured in the field. Stratification to 'on MDT' or 'RFT' was not possible, because these data were lacking in most of the hospital records.
- *Independence assumption*, meaning that admission (capture or marking) does not affect the chance of inclusion in the sample (recapture). The interval between the field study and the analysis of hospital records was 8 months. This allowed previously admitted patients to have returned to their home, enabling them to partcipate in the field survey. The choice of clinics where leprosy services are rendered is not random, but is related to the current caseload of patients requiring MDT. The accessibility of these clinics may not be adequate for all ex-patients in need of care, and may differ depending on geographical conditions, severity of the disability and varying attidues of health staff. These variations could not be further assessed. However, we have no reason to believe that geographical accessibility was related to the severity of disability.
- *Perfect matching* of individuals identified during admission to hospital and the the fields sample. Matching by soliciting a history of admission to the state leprosy referral hospital during the previous 2 years was considered sufficient to serve the purpose of application of the capture-recapture method. Possible recall bias of events such as hospital admission is unlikely, although the exact dates and duration of admission may be less acurately remembered. We did not use other identifiers, because addresses and even names may differ in time, and many patients do not recall their exact age.

STUDY METHODOLOGY

There may have been sampling errors in the field, related to different announcement strategies and impact. The willingness of leprosy victims to come forward to peripheral clinics may have differed. These factors are crucial factor for underlying assumptions of randomness and representativeness required for this method. In addition, the need felt by patients for admission to hospitals may vary over time, depending on changing physical conditions. An important factor hampering timely admission is the accessibility and affordability of services in terms of funds for transport and opportunity costs. The different age distribution between patients found in the field and admitted in the hospitals points to the fact that the younger people in particular were reluctant to come forward.

In addition, this study revealed that many patients had indications for referral to hospital. These patients were unknown to the health services. In general, the dynamics of leprosy patients reaching leprosy hospital, with and without referral, is still ill understood.

It is a fact that patients often reach leprosy referral hospitals without being officially referred.

In a study in Tanzania, using a demographic model,[1] the number of disabled patients predicted was four times greater than actually found in the clinics. This model was based on known age and sex specific disability incidence, estimated life expectancy of patients with and without disability, and the dynamics of disability state during and after treatment. This is a remarkably similar result. However, we have no means to prove that these results represent the reality. For that purpose, only a comparison with a whole population survey would be suitable.

CONCLUSION

The capture-recapture technique, in combination with a sample survey, appears to be a straightforward procedure to estimate the hidden population of disabled leprosy patients in need of care, and to assess the efficiency of a prevention of disabilities and rehabilitation programme. Comparison with demographic modeling revealed a remarkable consistency in the estimate.

We conclude that inviting disabled leprosy patients to come forward results in the capture of only a proportion of the actual cases in need of care. Obviously, the yield of invitation very much depends on the efficacy to convey the message and the willingness to come forward. Our sample therefore cannot be considered representative of the real number of leprosy patients with disabilities.

The actual coverage of clinics for MDT is likely to be different than that required for prevention of disabilities and rehabilitation. However, the patients who do report are likely to be motivated to participate in the prevention of disabilities and rehabilitation services.

We recommend that all disabled leprosy patients be registered in a special 'care' register, in order to enable their needs to be properly addressed.

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Studies on mode of detection of leprosy in China during the years 1981–1998

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Summary Along with the nationwide economic reform initiated in the early 1980s and the rapid decrease of leprosy endemic after the implementation of multi-drug therapy (MDT), the leprosy programme changed from 'vertical' to 'horizontal'. An evolution in the mode of detection of leprosy cases has consequently taken place. Based on the nationwide registration of newly detected cases, the profile of patients at detection has been studied. The proportions of cases corrected significantly with calendar years in detection by dermatological clinics, contact checks, 'clue survey' and mass survey, showing a significant increase in percentage of cases detected through dermatological clinics and contact checks, and decreases through 'clue survey' and mass survey. Detection of cases through dermatological clinics and voluntary reporting have become the main modes of case-finding during 1997–1998, accounting for 37·3% and 28·6%, respectively, where contact check accounts for only 9·1%. In areas with good dermatological services, a significantly higher proportion (75·9%) of cases was detected through dermatological clinics, where voluntary reporting and 'clue survey' were the main modes of detection in endemic areas. As regards confirmation of diagnosis, the great majority of cases were confirmed by leprosy units, even though they were detected in various other situations. Only 6·5% of leprosy cases were detected and subsequently confirmed by doctors in dermatologic clinics. The present modes of detection and their relation to demographical, epidemiological, clinical factors and health services are discussed. This study emphasizes the cardinal importance of the dermatological clinics in the detection of leprosy cases in China at the present time and hence the need to strengthen the training of doctors in these clinics, while continuously encourage their involvement in leprosy control.

Introduction

Early detection of leprosy patients and timely institution of anti-leprosy treatment are imperative to control and eradicate the disease. It has been observed that along with the

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nationwide economic reform initiated in China in the early 1980s and the rapid decrease of the leprosy endemic after the implementation of multi-drug therapy (MDT, the leprosy programme has changed from the vertical to the horizontal and a significant evolution in detection modes of leprosy cases has consequently taken place.

In order to monitor the endemic situation and to provide a useful basis for formulating the leprosy programme, a nationwide registration of newly detected leprosy cases has been undertaken annually since the 1980s in China. The profile of these patients at detection is presented and discussed in this paper.

Materials and methods

DATA COLLECTION

Data of the study were retrieved from the National System for Leprosy Surveillance[1], a population-based registry covering the whole country excluding three non-endemic areas, i.e. Beijing, Inner Mongolia and Shanxi as well as Taiwan Province, the Hongkong Special Administrative Region and the Macao Special Administrative Region. All data were collected with the specially designed forms and entered into computer, thus establishing a database for the period 1949–1998. Patients detected during the years 1981–1998 are analysed in the present study.

DETECTION MODES

Various detection modes have been implemented in China, often with variation over a specific time period. The main modes of detection as follow.

Voluntary reporting: actively and voluntarily reporting the suspected leprosy symptoms by patient himself/herself to medical institutions.

Dermatologic clinic: seeking medical care for skin lesions in dermatological clinic or department of dermatology in general hospital, the lesions having not been considered as leprosy by the patient.

Contact examination: routine examination of leprosy contacts, mainly referring to household contacts.

'Clue survey': group examination based on a specific clue or indication of leprosy, organized by a specialized institution of leprosy control.

Mass survey: systematic population survey, including examination in specific population groups, e.g. school children, etc.

Others: modes other than the above-mentioned, including seeking medical care in department of neurology, etc.

STATISTICAL ANALYSIS

One-way analysis of variance (ANOVA) and Bonferroni *P*-value were used for comparison of more than two means of quantitative data. Chi-square (χ^2) test was applied for statistical analysis of categorical data and χ^2 test for trend was used for the ordinal categorical data. Data analysis was performed using Epi-Info 5.0 (CDC, Atlanta, GA, USA) and SPSS 8.0 (SPSS Inc., 1989–1997).

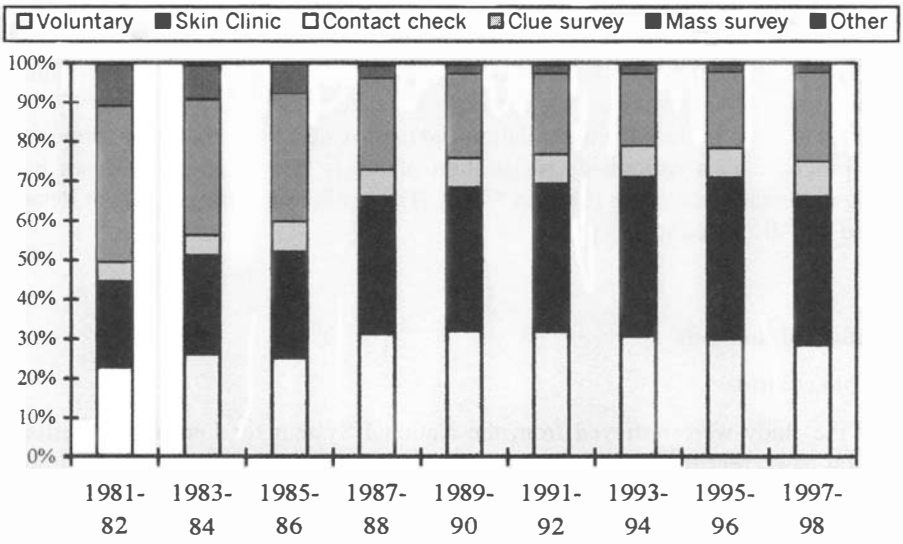

Figure 1. Leprosy cases by different detection methods and time period.

Results

A total of 31,115 leprosy patients detected during the years 1981–1998 were used to describe the detection methods of leprosy in China. Case detection through voluntary reporting fluctuated year by year, ranging 22·9% (246/1075) and 32·2% (1597/4967). During 1981 and 1998, there was an increasing trend in percentage of cases detected through dermatological clinics (21·9–37·3%) and contact check (4·7–9·1%), and decreasing trend in the percentage of cases detected through clue survey (39·7–22·5%) and mass survey (10·6–2·1%). Detection of leprosy cases through dermatological clinic and voluntary reporting have become the main modes of case-finding during 1997–1998, accounting for 37·3% and 28·6%, respectively, where contact check only accounts for 9·1% even with an increase in recent years (Figure 1). In addition, 'clue survey' resulted in detecting about 20% of patients in recent 10 years.

DEMOGRAPHIC CHARACTERISTICS

More men voluntarily report their disease than women (31·0% versus 27·0%), whereas women are more likely to be detected by family contact survey, 9·8% being in women and 6·7% in men. The percentages of detection are not significantly different between men and women in terms of case-findings through dermatological clinics or 'clue survey'. Detection modes in child cases are predominately family contact survey and mass survey, mainly the school survey. Dermatological clinics remain the main mode of detection of leprosy in workers, which is significantly higher than that in farmers even though the dermatological clinics are one of the main modes of detection in farmers. In farmers, the voluntary reporting results in 30·9% of patients and clue survey in 25·0%. Only 1·6% of workers and 7·1% of farmers were detected through contact examination (Table 1).

Table 1· Leprosy cases by different detection methods and demographic characteristics

Demographic characteristics	Numbers and percentages of patients by detection methods						
	No. of cases	Voluntary reporting	Dermatology clinic	Contact check	Clue survey	Mass survey	Others
Sex							
Male	22,935	7112	7998	1526	5420	762	117
(%)	*(100·0)*	*(31·0)*	*(34·9)*	*(6·7)*	*(23·6)*	*(3·3)*	*(0·5)*
Female	8180	2206	2891	798	1918	316	51
(%)	*(100·0)*	*(27·0)*	*(35·3)*	*(9·8)*	*(23·4)*	*(3·9)*	*(0·6)*
χ^2 test	–	$P < 0·01$	$P > 0·05$	$P < 0·01$	$P > 0·05$	$P < 0·05$	$P > 0·05$
*Age**							
<15	1130	212	248	401	193	74	2
(%)	*(100·0)*	*(18·8)*	*(21·9)*	*(35·5)*	*(17·1)*	*(6·5)*	*(0·2)*
15–29	9957	2866	3115	1138	2083	314	41
(%)	*(100·0)*	*(30·0)*	*(32·6)*	*(11·9)*	*(21·8)*	*(3·3)*	*(0·4)*
30–49	13,687	4418	4813	552	3374	456	74
(%)	*(100·0)*	*(32·3)*	*(35·2)*	*(4·0)*	*(24·7)*	*(3·3)*	*(0·5)*
50-	6741	1822	2713	233	1688	234	51
(%)	*(100·0)*	*(27·0)*	*(40·2)*	*(3·5)*	*(25·0)*	*(3·5)*	*(0·8)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·05$
Job							
Child	421	65	128	151	44	33	0
(%)	*(100·0)*	*(15·4)*	*(30·4)*	*(35·9)*	*(10·5)*	*(7·8)*	*(0)*
Student	618	144	223	147	67	35	2
(%)	*(100·0)*	*(23·3)*	*(36·1)*	*(23·8)*	*(10·8)*	*(5·7)*	*(0·3)*
Worker	1058	230	627	17	147	24	13
(%)	*(100·0)*	*(21·7)*	*(59·3)*	*(1·6)*	*(13·9)*	*(2·3)*	*(1·2)*
Farmer	27,589	8528	9112	1960	6884	963	142
(%)	*(100·0)*	*(30·9)*	*(33·0)*	*(7·1)*	*(25·0)*	*(3·5)*	*(0·5)*
Others	759	159	435	38	112	11	4
(%)	*(100·0)*	*(20·9)*	*(57·3)*	*(5·0)*	*(14·8)*	*(1·4)*	*(0·5)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$
Unknown	670	192	364	11	84	12	7

*Age at detection of disease.

Clinical and epidemiological aspects

The classification of leprosy, the numbers of lesions and nerves and the grading of disabilities according to mode of detection are present in Table 2. More MB patients were detected by voluntary reporting than PB, whereas dermatological clinics resulted in a significantly higher proportion (38·0%) of detection in PB patients than in MB (33·5%). Voluntary reporting remains the main mode for patients with nerve involvement but without a skin lesion, or with visible disability (WHO grade II), whereas dermatological clinics are more important for the detection of patients with skin lesions but without nerve involvement or disability.

ACCESSIBILITY OF HEALTH SERVICES

In the cities/counties at different levels, namely provincial capital (PC), prefecture city (PR) and county/township (CT) levels where the accessibility of health services is different, dermatological clinics remain the main mode of detection. However, the voluntary reporting and clue survey resulted in higher proportions in PR and CT levels than in PC level.

Table 2. Leproy cases by different detection methods and clinical characteristics

Clinical features	Numbers and percentages of patients by detection methods						
	No. of cases	Voluntary reporting	Dermatology clinic	Contact check	Clue survey	Mass survey	Others
Type							
MB	20,900	6757	7009	1350	5018	663	103
(%)	*(100·0)*	*(32·3)*	*(33·5)*	*(6·5)*	*(24·0)*	*(3·2)*	*(0·5)*
PB	10,215	2561	3880	974	2320	415	65
(%)	*(100·0)*	*(25·1)*	*(38·0)*	*(9·5)*	*(22·7)*	*(4·1)*	*(0·6)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·05$	$P < 0·01$	$P > 0·05$
Lesion							
None	1117	373	311	77	303	41	12
(%)	*(100·0)*	*(33·4)*	*(27·8)*	*(6·9)*	*(27·1)*	*(3·7)*	*(1·1)*
Single	3171	682	1134	383	811	144	17
(%)	*(100·0)*	*(21·5)*	*(35·8)*	*(12·1)*	*(25·6)*	*(4·5)*	*(0·5)*
Multiple	26,827	8263	9444	1864	6224	893	139
(%)	*(100·0)*	*(30·8)*	*(35·2)*	*(6·9)*	*(23·2)*	*(3·3)*	*(0·5)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·05$
Nerve							
None	2494	545	1139	241	455	107	7
(%)	*(100·0)*	*(21·9)*	*(45·7)*	*(9·7)*	*(18·2)*	*(4·3)*	*(0·3)*
Single	10,277	2830	3814	867	2353	359	54
(%)	*(100·0)*	*(27·5)*	*(37·1)*	*(8·4)*	*(22·9)*	*(3·5)*	*(0·5)*
Multiple	18,344	5943	5936	1216	4530	612	107
(%)	*(100·0)*	*(32·4)*	*(32·4)*	*(6·6)*	*(24·7)*	*(3·3)*	*(0·6)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P > 0·05$	$P > 0·05$
Disability							
None	17,655	5205	6443	1548	3797	576	86
(%)	*(100·0)*	*(29·5)*	*(36·5)*	*(8·8)*	*(21·5)*	*(3·3)*	*(0·5)*
Grade I	5071	1450	2000	348	1069	177	27
(%)	*(100·0)*	*(28·6)*	*(39·4)*	*(6·9)*	*(21·1)*	*(3·5)*	*(0·5)*
Grade II	8389	2663	2446	428	2472	325	55
(%)	*(100·0)*	*(31·7)*	*(29·2)*	*(5·1)*	*(29·5)*	*(3·9)*	*(0·7)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·05$	$P > 0·05$

Consequently, we considered 27 'historical' or present leprosy endemic provinces, municipalities and regions in the mainland as being from two groups according to facilities in dermatologic services at peripheral levels. The group with good facilities included Shanghai, Tianjin, Liaoning, Jiangsu, Shandong, Zhejiang, Fujian and Guangdong. Four provinces and one region, namely Yunnan, Sichuan, Guizhou and Hunan, where there are counties not achieving elimination of leprosy as public health problem, were considered as being endemic areas. In areas with good dermatological services, the majority (75·9%) of leprosy patients were detected through dermatological clinics, which was significantly higher than that in areas with relatively poor facilities where a significantly higher percentage of patients were detected through either voluntary reporting or 'clue survey'. Similarly, voluntary reporting and 'clue survey' were the main modes of case detection in endemic areas, while more than half the patients in non-endemic areas were found in dermatological clinics (Table 3).

CONFIRMATION OF DIAGNOSIS

Regardless of the detection modes or areas, the great majority of leprosy cases were

Table 3. Leprosy cases by different detection methods and areas

Socio-economic/ epidemic	No. of cases	Numbers and percentages of patients by detection methods: Voluntary reporting	Dermatology clinic	Contact check	Clue survey	Mass survey	Others
Residence							
PC	477	128	307	17	20	4	1
(%)	*(100·0)*	*(26·8)*	*(64·4)*	*(3·6)*	*(4·2)*	*(0·8)*	*(0·2)*
PR	3289	1036	1262	255	623	101	12
(%)	*(100·0)*	*(31·5)*	*(38·4)*	*(7·8)*	*(18·9)*	*(3·1)*	*(0·4)*
CL	27,349	8154	9320	2052	6695	973	155
(%)	*(100·0)*	*(29·8)*	*(34·1)*	*(7·5)*	*(24·5)*	*(3·6)*	*(0·6)*
χ^2 test	–	$P < 0·05$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$p > 0·05$
*Good facility**							
Yes	6407	905	4864	153	319	79	87
(%)	*(100·0)*	*(14·1)*	*(75·9)*	*(2·4)*	*(5·0)*	*(1·2)*	*(1·4)*
No·	24,708	8413	6025	2171	7019	999	81
(%)	*(100·0)*	*(34·0)*	*(24·4)*	*(8·8)*	*(28·4)*	*(4·0)*	*(0·3)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$
Endemic							
Yes	16,981	6390	3148	1693	5087	631	32
(%)	*(100·0)*	*(37·6)*	*(18·5)*	*(10·0)*	*(30·0)*	*(3·7)*	*(0·2)*
No	14,134	2928	7741	631	2251	447	136
(%)	*(100·0)*	*(20·7)*	*(54·8)*	*(4·5)*	*(15·9)*	*(3·2)*	*(1·0)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$

*Areas with good facilities in dermatological services at peripheral levels.

confirmed by leprosy units. A significantly higher proportion of confirmation by leprosy units was found in the areas without good facilities of dermatological services or with an endemic situation (Table 4). In areas with good facilities or without an endemic situation, confirmation by dermatological clinics accounted for 4·4% and 4·7%, respectively. Only 6·5% of leprosy

Table 4. Leprosy cases by confirmation units, facilities and endemic situation

	Number of cases	Numbers of patients by confirmation units: Leprosy unit	Primary clinic	Dermatology department	Others*
*Good facility**					
Yes	6407	6025	77	282	23
(%)	*(100·0)*	*(94·0)*	*(1·2)*	*(4·4)*	*(0·4)*
No	24,708	23,850	213	575	70
(%)	*(100·0)*	*(96·5)*	*(0·9)*	*(2·3)*	*(0·3)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$
Endemic					
Yes	16,981	16,701	69	191	20
(%)	*(100·0)*	*(98·4)*	*(0·4)*	*(1·1)*	*(0·1)*
No	14,134	13,174	221	666	73
(%)	*(100·0)*	*(93·2)*	*(1·6)*	*(4·7)*	*(0·5)*
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$

*Areas with good facilities in dermatologic services at peripheral levels.

Table 5. Leprosy cases by confirmation units and detection methods

Detection methods	Numbers and percentages of patients by confirmation units					
	No. of cases	Leprosy unit	Primary clinic	Dermatology department	Others*	Delay (mean ± SD)**
Voluntary reporting	9318	9013	121	144	40	3·58 ± 5·99
(%)	*(100·0)*	*(96·7)*	*(1·3)*	*(1·5)*	*(0·4)*	–
Dermatology clinic	10,889	10160	0	706	23	2·89 ± 5·30
(%)	*(100·0)*	*(93·3)*	*(0·0)*	*(6·5)*	*(0·2)*	–
Contact check	2324	2311	13	0	0	2·86 ± 8·28
(%)	*(100·0)*	*(99·4)*	*(0·6)*	*(0·0)*	*(0·0)*	–
'Clue survey'	7338	7201	137	0	0	5·23 ± 7·84
(%)	*(100·0)*	*(98·1)*	*(1·9)*	*(0·0)*	*(0·0)*	–
Mass survey	1078	1071	7	0	0	5·49 ± 9·43
(%)	*(100·0)*	*(99·4)*	*(0·6)*	*(0·0)*	*(0·0)*	–
Others	168	139	12	7	10	3·95 ± 5·34
(%)	*(100·0)*	*(82·7)*	*(7·1)*	*(4·2)*	*(6·0)*	–
χ^2 test	–	$P < 0·01$	$P < 0·01$	$P < 0·01$	$P < 0·01$	–
Total	31,115	29,895	290	857	73	3·34 ± 6·66
(%)	*(100·0)*	*(96·0)*	*(0·9)*	*(2·8)*	*(0·3)*	–

*Mainly including confirmation by department of neurology.

**ANOVA of mean delay of detection ($F = 136·0$, $P < 0·001$); statistically significant different between modes of detection except dermatological clinics versus contact check, 'clue survey' versus mass survey, and others versus any other mode.

cases were detected and consequently confirmed by doctors in dermatological clinics, and another 4·2% were detected by other doctors, mainly neurologists and then confirmed by dermatologists (Table 5).

DELAY IN DETECTION

For all the cases detected during 1981 and 1998, the overall mean delay in detection is 3·3 ± 6·7 years. Clue survey and mass survey are two mode of detection with a significant higher delay in detection than voluntary reporting, dermatological clinics or contact check. Delay in detection of leprosy cases through dermatological clinics was comparable with contact check, and significantly shorter than other modes of detection (Table 4).

Discussion

Besides importance for control of leprosy, early detection of the disease is essential to prevent deformities and disabilities. Modes of detection of leprosy patients can be classified in several categories: systematic population survey, voluntary reporting, surveys of specific population groups, surveillance of high-risk groups, and combined multi-disease detection and care. It should be stressed that there is no leprosy control without organized detection.[2] Leprosy has been successfully controlled in China through continued efforts for more than 40 years.[3] During this period, three systematic population surveys in 1958, 1965 and 1972 were carried out in the country which have played an important role in detection of leprosy patients, especially the backlog of patients. However, such a method cannot be recommended for

the present situation in China because it is time-consuming and expensive, resulting in poor cost-effectiveness, although it still has its place in prevalence surveys.[2]

During the study period, detection of cases through contact examination and mass survey accounted for only 7.5% and 3.5%, respectively, much lower figures than those observed in some leprosy endemic areas.[4,5] Moreover, the proportion of patients detected by 'clue survey' and mass survey have significantly decreased through the years, which may be mainly due to the decreasing application or insensitivity of these two methods in the recent years. However, the dermatological services remained the main mode of case detection and significantly increased year by year, understanding the importance of dermatological clinics in case-finding. In China, especially in endemic areas, some doctors in dermatological clinics have shown increasing interest in leprosy and many dermatologists are now willing to be involved in leprosy control.[6] However, some operational factors may also affect the high detection in these clinics, such as incentives which may encourage doctors to bring forward the suspected patients, including those in whom over- or wrong diagnosis may be a possibility. This can be supported by the fact that only 6.5% of leprosy patients detected through dermatological clinics were confirmed by themselves. Taking these points into consideration, further professional training on leprosy should be provided to doctors in dermatological clinics while continuously encouraging their involvement in leprosy control.

The proportion of voluntary reporting in the present study (29.9%) was comparable with that observed during 1995–1997 in Khulna, Bangladesh, where it accounted for 33%, but the proportion found by contact examination in our study is much less than that in the latter.[7] In India, more women were detected by general survey and contact survey, while the proportion of detection by referral, voluntary reporting and school survey among women was less than among men.[8] In the present study, the difference between men and women was not found in detection modes of dermatological clinic and clue survey, but men were more likely to voluntarily come forward and women to be detected by contact examination, which is similar to that observed in Khulna of Bangladesh.[7] This may be due to the fact that in the countryside, especially the endemic areas, the men usually leave home to go out to work and have less chance of being examined and are more likely to voluntarily report the disease if any symptom or sign occurs. The proportion of dermatological clinic cases in younger age groups was significantly lower than that in elder age groups, and in the farmers it was lower than in other workers. The association of lower proportion with specific age groups and jobs could be related to the finding that children tend to be detected through contact survey,[9] and farmers have a lower accessibility to hospitals, including dermatological clinics.

More patients with MB leprosy and/or visible disability were detected by voluntary reporting as compared to patients with PB and/or without visible disability. This obviously implies that the MB lesions and/or visible disability were easily noted by patients themselves and voluntarily brought forward. It is interesting that through dermatological clinics the patients with PB leprosy and/or without nerve involvement or visible disability can be detected to a greater extent of 38%, 45% and 39.4%, respectively.

It is found from this study that there were differences in detection modes between the patients from different areas in terms of resident levels, health service facilities and endemic situations. The differences may be related to accessibility of health services and implementation of leprosy control programs in specific areas. This implies that the detection modes should be adapted appropriately and that health education should be strengthened according to the specific situation at the local level.

It was interesting to find that delay duration in detection of cases through dermatological clinics was comparable with clue survey, and significantly shorter than other modes of detection, including voluntary reporting and mass survey. It is known that the early detection of leprosy in China does not depend upon active case-detection. Notification of cases through dermatological clinics has been a good method of case-finding, which not only detected cases relatively soon after have become symptomatic but also before most have developed grade-II disability.[10]

Based upon the present study, it has been known that there has been a significant evolution of detection modes during the past years. Through these modes, a total of about 1800 leprosy patients have been detected annually in China in recent years. However, the Leprosy Elimination Campaign (LEC) carried out recently in some leprosy endemic areas has shown that the actual number of leprosy patients was significantly higher than reported figures, including multibacillary cases, suggesting that our present detection modes are not sensitive enough to find out the leprosy cases, at least in the endemic areas.

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The experience of self-care groups with people affected by leprosy: ALERT, Ethiopia

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Summary This paper describes the development of self-care groups in Ethiopia by ALERT, and the successes and failures experienced in the process. The groups were started in 1995 in response to two main problems, the increasing number of people dependent on ALERT to heal their wounds despite years of health education, and the limited financial resources of ALERT for wound healing supplies. By December 1999, there were a total of 72 established groups. Group membership was voluntary. There have been a number of positive outcomes. Group members have taken up responsibility for managing and monitoring their own wounds and supplying their own wound healing materials. More attention is paid to their personal hygiene and personal appearance. They also report increased confidence to participate in society, retored dignity and self-respect, and a sense of belonging within the community. In addition, some members have started to pay more attention to their local environmental hygiene by building pit latrines and waste disposal sites. The ALERT staff involved in this initiative had to change their role from that of a leprosy service provider to a self-care group facilitator, but not all were successful in making this transition. The remaining challenge for the programme is sustainability and further development through the National Tuberculosis and Leprosy Control Programme, The Ethiopian National Association for Ex-Leprosy Patients and possibly other organizations too.

Introduction

This paper outlines the reasons that prompted the establishment of self-care groups, their development and the outcomes.

In 1995, ALERT staff expressed concern about the increasing number of people affected by leprosy who continued to use the ALERT hospital and field clinics for their wound management. In short, the traditional approach for the prevention and management of ulcers, the didactic, health education talk or lecture which might or might not include a practical demonstration of soaking, oiling, scraping, wound trimming and dressing,[1] had disappointing results. The dressing of wounds was time consuming for the leprosy workers, who also expressed concern about the dependency of the people upon this service. There were limited

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financial resources available for wound healing materials, such as antiseptic, blades for trimming, Vaseline and bandages. These factors led ALERT staff to examine alternative methods of addressing the problems of wound management and the shortage of resources. It was decided to trial the use of self-care groups.

Self-care groups

The formation of a group of people is a natural phenomenon within society. The most effective groups have a specific aim, such as addressing a particular problem, bringing about change, or supporting one another.[2] Group development is a dynamic process; some groups develop well and achieve results, whilst others remain fragmented or disband. Successful groups go through four stages: 'forming, storming, norming and performing'.[3] 'Forming' or starting is when a group of people come together with an apparently common objective. 'Storming' or conflict takes place when individuals within the group begin to express their previously unspoken reasons or agendas for joining the group and try to move the group in the direction they choose. It is essential that the objective of the group is clarified and individuals either agree to the objective or leave the group. 'Norming' or sorting out occurs when conflicts between individuals are resolved and the group starts to identify itself as a single unit, working towards the agreed objective. Finally, 'performing' or producing takes place when the group starts to achieve the objective. Some groups reach the 'producing' stage quickly, whilst others vacillate between the 'storming' and 'norming' stages, due to various agendas people bring and which can only be dealt with over time. Most groups that fail do so in the 'storming' stage. It is important that facilitators or groups understand these stages in order to respond appropriately.

The management of impairment, regardless of the health condition, whether physiological or psychological, is a challenge to the person affected, the family and community as well as the service providers. For some, a health condition may also result in problems of activity limitation and participation restriction.[4] To address some of these problems, people around the world with a similar health condition have formed local and international support groups, such as mental health groups,[5] addiction related recovery groups,[6] diabetes groups,[7] spinal injury groups[8] and cancer groups,[9] to name but a few. However, there is no such documented evidence of similar support groups for people affected by leprosy, and in particular, groups that address problems related to wound prevention and management.

Self-care groups are a form of support group. The ALERT self-care group philosophy, in the context of people affected by leprosy, is based on the premise that wound healing is the responsibility of those directly affected and uses the group dynamics of encouragement and accountability to support one another in wound management and obtaining wound healing materials.

Thus ALERT set up three self-care groups in 1995 on a 6-month trial basis in a colony area near Shashemane, 250 km south west of Addis Adaba, where there was a shortage of wound healing materials and a tradition of dependency upon a local hospital and clinic services.

Guidelines for 'establishing self-care groups', 'facilitating and running self-care groups', and a 'self-care data form' were developed by the six staff members who worked in the leprosy control programme.

ESTABLISHING SELF-CARE GROUPS

There were three main stages in the establishment of a self-care group: an introductory meeting, screening of possible members, and finally the establishment of the group.

The introductory meeting with possible group members was to explain the philosophy of the self-care groups:

- Group membership was voluntary (only those who wished to take responsibility for their own wound management could volunteer).
- Wound healing materials had to be provided by the group members themselves (not by ALERT).
- Members were required to participate actively in problem solving discussions, to develop practical solutions for wound healing and prevention and to monitor each other's progress.
- Canvas shoes with microcellular rubber (MCR) insoles were available at a subsidized cost of $1.25 US at the group meeting[10] (this footwear was also available at the leprosy clinic for any person with plantar anaesthesia).
- There were no handouts in this programme, such as clothing, food or monetary gifts.

There was also an opportunity for those present to ask any questions.

Potential members were screened according to membership criteria: diagnosed as having leprosy (on treatment or released from treatment) with 10 g monofilament anaesthesia of one or more points on the hands or feet.[11,12] Beggars were usually excluded from the groups but if a beggar demonstrated positive behaviour and wished to change the 'begging use' of wounds, then the group members and facilitator could consider his/her request. A list of members was made and based on discussion with the members they were allocated into groups.

The ideal size for a group meeting to maximize participation, was between 7 and 10 members.[13] This number allowed everyone to speak, although the quieter people would say less. However, the size of the group varied according to the locality and needs of the people. For a meeting to take place, at least 50% of the members had to be present.

Once the membership of a group was established, the members chose a group leader. The leader was responsible for running and managing the group and reporting any problems encountered within the group to the facilitator. The group, along with the facilitator, decided on a meeting place at a group member's home that was convenient for the majority of the members, and a timetable of meetings.

Group meetings were held every 1 or 2 weeks as decided by the members, and the monthly meetings were attended by the facilitator. The meetings normally lasted between $1\frac{1}{2}$ and 2 h.

GROUP MEETINGS

Meetings normally followed a preset format. The group members, including the group leader and facilitator (when present), sat in a circle. The leader and facilitator were responsible for creating a group environment where everyone was respected and everyone felt free to participate in the discussion, expressing their opinions as well as their doubts or ignorance. The meeting began with an introductory welcome and an update on issues of importance and interest to the group. The facilitator or group leader would usually open the discussion in a culturally acceptable manner, followed by general questions about the weather, harvest, cattle and family for example. A discussion about each member's personal appearance and hygiene followed, with suggestions if necessary, for improvement.

The meeting continued with the inspection of each group member's hands and feet. The group members took their turn to sit on a stool in the middle of the circle, where they showed their hands and feet for inspection to the other members. Following the inspection of the skin condition and wound status, questions and comments could be put forward by any of the group members. The group discussion was ideally dynamic, with adequate time for each person. If there were no questions or comments, the group leader or the facilitator would suggest points for discussion by asking open and probing questions. If on the other hand, the discussion was going round in circles, the facilitator or group leader summarized the main points and brought the discussion back on track. At the end of the discussion, the summary focused on the action and solutions to be taken by each member, and on the role of the members in supporting each other because the outcomes would be monitored at the next meeting.

If a solution was developed which was not considered appropriate by the facilitator or group leader, it was their responsibility to make sure the group had a correct understanding of the problem being discussed, and appropriate solutions were then developed. For example, rest and clean dressings could not manage the problem of osteomyelitis; instead the group member should be referred to the hospital for surgery.

At the end of the meeting, the facilitator or group leader would investigate the reason for any absentees, then close the meeting, thanking the members for their participation, interest and results.

The facilitator visited each group once every 4 weeks. At these meetings, the facilitator listened to the reports of previous meetings and addressed any problems, assisted the group leader with the facilitation of the meetings and brought footwear for the members to purchase. The self-care data form was also completed at this meeting. This form recorded the wound status data and the solutions developed for each group member during the first 6 months of group membership.

After the 6-month period, the group members decided whether to continue or not. If the members decided to continue their meetings, they could request the facilitator to attend, but he/she would not continue to fill out the self-care data form, only the group membership register.

MEMBERSHIP CANCELLATION

Members could be asked to leave the group if they did not participate actively in the group discussion or implement the advice given, if they were dominant or aggressive, if they tried to divert the aim of the group for other purposes, or were absent without notifying the group for more than four successive meetings.

TRAINING OF STAFF

The staff who took up the task of self-care group facilitation worked in the ALERT leprosy control programme. There was no formal training for the staff when the programme started. However, the six staff involved in the initial trial developed the guidelines from which they worked and gave each other support and advice. This process in itself proved to be a form of 'on the job' training.

In 1996, it was decided that the programme should be expanded in other areas of the leprosy control programme, so a 4-day 'introduction to self-care' workshop was conducted for the staff. However, this introduction was not sufficient for many of them to establish well

functioning groups; and in 1998, a 4-day course was developed and conducted by the authors on 'The principles of adult learning, the art of facilitation and the procedure for setting up and running a self-care group'. The content of the training was kept simple. It was based on the understanding that the group members already knew how to prevent and heal their wounds (they had received years of formal health education), and since membership was voluntary it was assumed they would be motivated to take their responsibility for wound management. Therefore, the challenge to the staff was to develop constructive group dynamics, so the members would agree to implement solutions to heal their wounds and monitor each other's progress. The basic skills required to develop effective groups were discussed and demonstrated. However, the proficiency of the facilitator to listen and ask appropriate questions would be acquired as they gained experience in running groups. Only those leprosy workers who were interested in setting up self-care groups were encouraged to do so. However, the facilitators who ran groups received a daily per diem for each visit made, in line with the leprosy control programme procedures for staff when they leave their duty station. This per diem was therefore an incentive for some to establish groups.

The biggest challenge faced by the facilitators was the 'storming' stage in the group development. This stage is characterized by intra-group conflict, when the purpose of the group is being challenged because the members' previously unspoken agendas for joining the groups are verbalized. These unspoken agendas included the expectation that if they attended the meetings, they would receive handouts from the programme: wound dressing materials, clothing, grants and assistance with house building, for example. These handouts were available in the past. It was essential, therefore, that the facilitator held fast to their understanding of the self-care group philosophy so that the group could work through this stage; otherwise, the facilitator would be undermined and dispirited and the group in turn would fail. The other main challenge was the self-perception of the leprosy worker. If they wished to maintain the role of service provider with the white coat status, they would never make the transition to facilitator.

Supervision by those responsible for the programme (a social worker, therapist or proficient supervisor/facilitator) was essential and included an assessment of the group development, the skills of the facilitator and the wound management status. Supervision times also allowed the facilitator to raise their own questions and problems, plus those of the group that they could not address. At different stages in the group development, the facilitator faced different challenges that had to be managed. Sometimes, the facilitator learned more easily by observing the supervisor facilitating the group from time to time. They could observe the techniques used to control dominant members or to encourage quiet ones, the development of the discussion with well-framed questions and the important skill of listening. Assistance was usually required with completing the self-care data form.

No formal training sessions were conducted for the group leaders. It was expected that they would learn by example, by watching and listening to the facilitator and supervisor as they conducted the meeting.

Findings

GROUP DEVELOPMENT

Following the initial trial of 6 months, the programme was not formally evaluated, but based on the observation of improved wound cleanliness, healing of some wounds, reduction in size

of others, improved skin condition and the interest of the group members in continuing, plus the desire of others wishing to join groups, it was decided to expand the programme. By December 1999, there were 34 functioning groups in Shashemane, 14 groups in Wolkeite, four in Addis Adaba and 20 in other areas of the ALERT leprosy control programme area with a total membership of 728.

The group sizes varied. In 'leprosy villages' and urban areas where there were many group members, groups of 8–15 were formed, whereas groups of 3–6 were formed in rural areas where the members could be widely scattered. In contrast, members of small groups in some areas opted to join together to form one larger group, with a maximum membership of 15–18 people. Some members chose to walk distances of up to 2 h, evidence of their commitment to the group.

With the exception of four groups, all opted to meet at group members' homes. Two of the four groups chose to meet at health stations because of the high level of stigma associated with leprosy in those areas, whilst the other two groups met in the homes of people (not affected by leprosy) who offered them as a more convenient meeting place than any of the group members' homes.

Without exception, all groups met every 4 weeks. Of these, 10% did not meet more often, 80% met every 2 weeks, and 10% met weekly. Every 4 weeks, the groups were visited by the facilitator and by May 1999, 16 well established groups in Shashemane and four in Wolkeite only required visits every 8 weeks. This in turn allowed the facilitators more time to establish new groups.

Of the 96 groups that were formed since 1995, 72 continued to meet (not one took the option to stop meeting after the first 6 months). Nine groups amalgamated due to declining membership caused by death, members moving away and others losing interest to continue. Fifteen groups failed because they did not develop past the storming phase due to intra-group tensions and alternative agendas or due to the limited skills and/or commitment of the facilitators.

WOUND MANAGEMENT MATERIALS

As part of the self-care philosophy, group members had to provide their own materials for wound management and they have adopted innovative, low cost solutions.

At first, some of the group members were reluctant to use their materials. They believed that wounds would not heal without the white bandage (it emerged that some members believed that the white bandages were impregnated with special healing qualities), without antiseptics and with only their own limited skill and knowledge. Some members believed that their disease gave employment to the staff and it was their right to receive medical wound care. Following discussions on these subjects and examples of wound healing by some of the group members, the sceptics in time decided to take control of their own wound problems. Wounds were cleaned using the water available and soap (but soap is not essential). Wounds were covered with a piece of cloth, usually a piece of old clothing or a shawl. It was either tied in place or secured by wearing a sock (even if full of holes!). The cloth pieces were washed and reused. An alternative to cloth were the cellulose strips from the stem of the false banana leaf, which were sterile and moulded easily around the limb. These strips were up to 1 m long and torn to the desired width. A constant supply was available wherever the trees were grown in Ethiopia. At first, some of the members were reluctant to use these strips because they were considered to be a 'traditional' material, but

following the wound healing results of others using false banana 'bandages' they changed their minds and began to use them.

The core from a maize corncob was an excellent scraping tool; it was easy to hold and not as abrasive or as hard as a stone. Instead of surgical blades for trimming ulcers, razor blades were used, usually with considerable proficiency. If someone was not able to use a blade due to hand or visual problems, a family member usually trimmed the wound and if this was not possible, a group member would help instead.

To seal water absorbed into the hands and feet after soaking, Vaseline was bought by some members whilst others went without; some bought cooking oil as a cheaper alternative. Sometimes group members contributed a few cents to buy oil that was then distributed between them.

On no occasion were group members supplied with wound healing materials from the ALERT facilitators. If a group member chose to go to the local hospital or clinic for wound dressing they would be questioned by the group members as to their reason for attendance. If their reason was considered invalid, the member would be given advice and support to help them take up their responsibility for their wound management.

WOUND MANAGEMENT RESULTS

The self-care data form was developed for monitoring the wound status of the group members, but the skill of some of the facilitators in completing the forms was variable. This problem could be overcome in future by more training. Nevertheless, the forms were found to be of value for routine supervision purposes that included the approximate changes in wound size, wound healing, skin condition and the occurrence of new wounds. It should be pointed out that this programme was not established on research protocols but as an operational programme to assess whether group members would assume responsibility for their own wound problems. As a result, it is not possible to present statistically reliable wound management results for this paper.

However, an informal follow-up was conducted in December 1999 in two distinct communities. The first was the former leprosy colony near Shashemane where the group members live in close proximity and most people are involved with agriculture. The other area was Wolkeite, where the group members live alongside the general population within a more sparsely populated area and most of the people are traders and farming is of less importance.

The authors conducted the follow-up with 173 group members, 126 in Shashemane and 47 in Wolkeite, who were present on the day that the authors attended group meetings according to the routine programme. The follow-up took place between 12 and 50 months after the intake. The follow-up data collection was more exact than that recorded on the self-care data forms (at intake and at 6 months) because any break in the continuity of the dermis was recorded as a wound, with the result that the wound count was higher than if the original facilitators had collected it.

In Shashemane, the number of people with foot wounds at intake was 51, at 6 months 36, and at follow-up 42; and in Wolkeite the number with wounds at intake was 15, at 6 months 12, and at follow-up 8. In Shashemane the total number of dorsal and plantar foot wounds reduced from 76 to 50 between intake and 6 months, but rose from 50 to 52 between 6 months and follow-up; and in Wolkeite the reduction was from 34 to 14 between intake and 6 months and from 14 to 11 between 6 months and follow-up.

In Shashemane, the number of feet with one or more wounds at intake was 65, 44 feet at 6 months and 46 at follow-up; and in Wolkeite, there were 20 feet with one or more wounds at intake, 13 feet at 6 months and 10 at follow-up.

In Shashemane, the number of feet with one or more wounds at intake was 65, 44 feet at 6 months and 46 at follow-up; and in Wolkeite, there were 20 feet with one or more wounds at intake, 13 feet at 6 months and 10 at follow-up.

It should be noted that the change in the number of people with wounds, the number of wounds or feet affected at intake, at 6 months or at follow-up does not refer to specific individuals, wounds or feet, but rather to the overall wound total because some wounds were healed and some new ones had developed. Without exception, all wounds that were present at intake were smaller at follow-up. Some of these wounds were impossible to heal completely due to the condition of the skin, the underlying soft tissues and the altered bony structure of the foot, in addition to the need to carry out activities of daily living.

Hand wound results were variable and appeared to be related to working and seasonal conditions rather than the skill of the group members to prevent them. Some hand wounds were healed quickly whilst others resulted in bone loss. Superficial hand wounds were not recorded on the self-care data forms (the facilitators said they would heal quickly and therefore was no need to record them!) and the accurate recording of bone loss was problematic for the facilitators, therefore hand wound data are not included in this paper.

At any one time, 90% of the total group membership had well hydrated skin, 85% had clean and well-trimmed wounds and 80% of the wounds were covered (superficial wounds were often left uncovered), and 95% wore footwear, which despite the various stages of wear, did afford varying degrees of protection.

Self-care groups were unable to stop their members getting wounds because of the very nature of the sensory and autonomic dysfunction and altered anatomy of the foot and hand. Rather, the most important function of the groups was to enable the group members to develop a positive attitude towards their responsibility in the wound management process. Some of the staff considered the attitude and behavioural change of the members more important than the specific quantitative wound healing results, given that wound occurrence is inevitable.

FACILITATORS

Some leprosy workers made the transition to facilitator easily, whilst others, even after training, remained as formal health educators and did not believe in the basic philosophy of the groups. Of the 53 leprosy workers in the control programme, 17 succeeded in establishing groups, eight started but failed and 28 did not start at all.

Unexpected outcomes

In addition to the expected benefits of the self-care groups, there were a number of unexpected outcomes.

Group members mentioned feelings of 'belonging to a group', improved self respect and dignity and confidence to participate socially. Others who required help with harvesting or house repairs received assistance from other group members and even their families. The following quotations from the group members illustrate these outcomes:

- 'We participate in society now. For example, when we attend a coffee ceremony, we don't hide our hands and feet any more. Now we sit with outstretched feet, show our hands when eating and gesticulate when talking'.
- 'We don't go to the hospital or orthopaedic workshop for ulcer treatment any more. Why should we? We can do it ourselves'.
- 'Because we no longer smell and are surrounded by flies, my daughter married into a non-leprosy family'.
- 'Once we were dependent on the hospital and had wounds, now we are independent and we don't have wounds because we can heal them ourselves; now we have our dignity and self respect'.
- 'Sometimes we help one another with work, harvesting for example, so that members can rest. We are becoming like a family and share occasions together'.

The group members made important suggestions to develop the programme. One suggestion resulted in an increased selection of subsidized commercial footwear from ALERT. Additional styles of canvas shoes with MCR were introduced and PVC boots with MCR for use in the rainy season, all at a cost of $1.25 US a pair to the group members.[14] However, some members with shortened feet liked the PVC boots for cosmetic reasons, and those with drop feet wore the boots because they act as a drop foot splint. These boots were worn during the dry season too, but with no reported problems of heat burns or excess sweating that might cause wounds or prevent existing wounds from healing. A smart looking leather jogging shoe with MCR at a cost of $5 US was also available.

Another suggestion resulted in a limited number of group members taking an increased interest in environmental hygiene, with the result that some have dug their own pit latrines and pay greater attention to the cleanliness of their compounds.

Other requests included the availability of family planning measures given the shortage of land to support their families, loans, technical input to improve their agriculture output and better access to eye care, which could be addressed in the future.

In the Wolkeite area, the group members introduced a system of fines to punish those who failed to implement the advice given, because the 'purpose of the group was being dishonoured as well as the other members'. Those fined usually paid a few cents, but on occasions as much as $1 US would be agreed upon by the group. These same groups also introduced a series of claps, one two or three, to reward improvement and good wound prevention and healing.

The self-care programme also provided a useful structure used for carrying out a number of studies by staff and trainees at ALERT, such as 'Who is at risk of developing wounds and why?' and 'Tool handle shapes for those with upper limb motor paralysis'. Other studies were proposed, for example, a comparison of the quality of life between those affected by leprosy, those affected by leprosy who are group members, and the general population who live in the same area; and an investigation into the use of the group structure for the implementation of a loan scheme.

The self-care programme was established to address the problems of wound management but the groups have provided more than just wound management support to one another. Given the unexpected outcomes of the programme, some staff asked why the poeple affected by leprosy could not decide on the criteria for group membership. In the future group members and potential members should be asked what criteria they would recommend.

Costing

Costing this initiative was difficult, since it was an integral part of the prevention of disability programme within the MDT programme. Each group was visited once every 4 weeks by the local area leprosy supervisor or facilitator for the first 6 months following the initial setting up stage, which required four to six visits. The transportation costs varied fom area to area; in Shashemane the costs were small as the groups were close together, but in Wolkeite they were much higher because the groups were up to 50 km from the duty station. In addition to the facilitator, a supervisor from ALERT headquarters would sometimes visit the groups but not all groups were supervised. Groups in distant, isolated areas were not supervised because of the time required and the costs involved.

It was estimated that the cost of establishing and running a group was approximately $20 US per visit ($220 to set up and facilitate a group for 6 months). This costing was based on the facilitator's and driver's daily salary, their lunch allowance, fuel, maintenance, insurance and lubricants for the vehicle (excluding vehicle purchase and depreciation), for a 50 km round journey from the duty station. Supervisory visits by ALERT headquarter based staff cost more because of the distance from ALERT to the duty station and the overnight per diem.

In addition to the costs of the programme, there were savings in the use of hospital services for wound management. Although the reduction was not measured, the hospital at Shashemane which is the main leprosy referral hospital for the south of Ethiopia, reported a decline in the number of people attending for wound care after the self-care programme was started.

Issues of sustainability

This programme has succeeded in setting up a number of self-care groups for people affected by leprosy, however the programme needs to be expanded throughout Ethiopia. ALERT cannot undertake this task because all leprosy related activities have now been integrated within the National Tuberculosis and Leprosy Programme (NTBLP) who will continue to strengthen this programme.

Another option considered for the expansion of this programme was its integration within the Ethiopian National Association for Ex-Leprosy Patients (ENAELP). The self-care philosophy and development process could also be taken up by community development projects, working in conjunction with the NTBLP and ENAELP.

Conclusions

This paper reports on the self-care programme established by ALERT, as part of the MDT programme. The programme successfully established a number of self-care groups for people affected by leprosy. The main function of the groups was to encourage the members to take responsibility for wound management, which was achieved. The number of wounds reduced most notably during the first 6 months of joining a group but these results were maintained over time. The group members reported a number of qualitative benefits, in particular improved self-respect and dignity and increased participation in society.

Seventy-two groups developed useful outcomes, nine groups amalgamated and 15 groups failed during the 'storming' stage of the group development. Of the 53 leprosy workers who received training in self-care groups, 17 succeeded and eight failed in establishing groups, and 28 were not able to make the transition from health service provider to facilitator or were not interested for personal or environmental reasons, such as working in areas of high stigma or with isolated people.

It was not possible to cost the initiative exactly, due to the integrated nature of the MDT programme, but it was estimated that the cost per group visit was approximately $20 US. There were also some cost savings to the health service.

This initiative shows that it is possible to set up self-care groups, although some failure must be expected. The benefits to the individual members can be enormous, enabling them to manage their own wound problems, giving them a sense of control over their impairments, making other changes to their life style and environment and enabling them to participate more fully in society.

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Osteoporosis, bone turnover and hypogonadism in elderly men with treated leprosy

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Summary In male hypogonadism associated with bone loss, it is important to determine whether bone loss continues with ageing and an increased risk of fracture. We studied bone metabolism in 86 male leprosy patients, who were classified according to the presence or absence of osteoporosis. Osteoporosis was present when men had lumbar compression fractures or a mean BMD-2SD that of normal Japanese men in each age decade. Four men had fractures. Serum concentrations of 1,25-dihydroxyvitamin D and high-sensitivity parathyroid hormone were almost normal in both groups, whereas free testosterone and oestradiol were significantly lower in the osteoporosis group than in the non-osteoporosis group (free testosterone: $P < 0{\cdot}01$, oestradiol: $P < 0{\cdot}05$). The urinary concentrations of pyridinoline and deoxypyridinoline, as a marker of bone absorption, were significantly higher in the osteoporosis group than in the non-osteoporosis group (pyridinoline: $P < 0{\cdot}01$, deoxypyridinoline: $P < 0{\cdot}01$). The serum concentration of osteocalcin, a marker of bone formation, was significantly higher in the osteoporosis group than in the non-osteoporosis group ($P < 0{\cdot}01$). Elevated concentration means that bone repair is increased possibly because of compensation mechanisms for increased bone loss. In the osteoporosis group, hypogonadism occurred, and high bone turnover continued even in older men. We recommend clinical studies of treatment such as replacement therapy to prevent bone loss and increasing risk of fractures in older men with leprosy.

Introduction

In male hypogonadism, sex hormones (testosterone and oestrogen) are the main factors regulating bone mineral density (BMD).[1–5] We see male leprosy outpatients with or without

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complaints such as back pain and discover osteoporosis in some of them on X-ray. We previously reported that hypogonadism contributes to bone loss in male leprosy patients.[6–9] We measured the cortical thickness of the 2nd metacarpal bone index in 499 leprosy patients whose ages ranged from 40 to 70 years and more.[6] The metacarpal bone index of 238 male patients with lepromatous leprosy was lower than that of 139 female patients with lepromatous leprosy. We also measured bone mineral densities in 31 male leprosy patients and 31 age-matched healthy controls, and we found that serum concentrations of free testosterone and oestradiol concentrations were significantly lower and luteinizing hormone concentrations significantly higher in leprosy patients than in controls.[7] Bone mineral density of the forearm significantly correlated with free testosterone concentrations ($r = 0{\cdot}689$, $P < 0{\cdot}0001$). We then conducted a mass osteoporosis examination and measured the bone mineral density of 353 leprosy patients (197 men and 156 women) and serum concentrations of free testosterone in 81 of the men.[8] More than 30% of men at all ages had osteoporosis. Serum concentrations of free testosterone in men ranged from almost 0 to normal at all ages, and bone mineral density was significantly correlated with serum concentrations of free testosterone. In another study, we used histopathological and histomorphometric methods to compare the degree of testicular damage with that of trabecular bone loss in autopsy cases.[9] Trabecular bone volume was maintained in patients with nodular Leydig cell hyperplasia in the testes, which secrete androgen hormone, whereas testes without Leydig cell hyperplasia showed a loss of trabecular bone volume. These findings indicated that secondary gonadal dysfunction caused by testicular atrophy may be a factor in osteoporosis in male leprosy patients and that Leydig cell hyperplasia apparently preserves bone volume. From the combined results of these previous studies, we concluded that the orchitis caused by *Mycobacterium leprae* in their youth contributed to the development of osteoporosis in ageing male leprosy patients.

Today, in Japan patients with leprosy are often in their 70s. In male hypogonadism associated with bone loss, the most interesting question is whether high turnover continues in older men, as it does in postmenopausal women, thereby increasing the risk of fracture.

To study bone turnover, we measured urinary concentrations of pyridinoline (Pyr) and deoxypyridinoline (Dpyr), and serum concentrations of osteocalcin (OC). Urinary Pyr, a cross-linking intercollagen molecule, and Dpyr, an analogue of Pyr, are known as markers of bone resorption.[10–14] Serum osteocalcin, which is a bone-specific protein secreted by osteoblasts,[15] serves as an index of bone formation.[13,16] To study bone metabolism, we compared the serum 1,25-dihydroxyvitamin D [1,25$(OH)_2$D], parathyroid hormone (PTH), and gonadal steroid (free testosterone and oestrogen) concentrations between those with and those without osteoporosis among a group of male leprosy patients.

Materials and methods

SUBJECTS

Eighty-six male leprosy patients, aged 45–83 years (average: 65·5), agreed to have blood, urine, and bone mineral density tests conducted. They had all lived for several decades at the national leprosarium on a small island in Japan, had eaten almost the same diet, which was calculated to provide a certain amount of calories and nutritional balance, and had normal activities of daily living. None of the patients was receiving androgen replacement therapy or

steroid therapy before this study. Only five men had been previously treated for osteoporosis (vitamin D replacement by oral or intramuscular calcitonin). Informed consent was obtained from each patient, and we explained the results and treatment plan to all patients. Approval for this study was obtained from our institutional ethics committee.

BMD AND BODY CONSTITUENT DETERMINATIONS

BMD data, in grams per square centimeter, were determined by dual energy X-ray absorptiometry (DXA) with a Hologic QDR-4500 densitometer (Biologic Inc., Waltham, MA, USA). The standard sites checked were the lumbar vertebrae (L2–L4). Kin *et al.*[17] measured BMD of 248 healthy Japanese male volunteers grouped according to decade of age. The result was 1·027 ± 0·084 g/cm^2 in those aged 20–29, 1·195 ± 0·128 g/cm^2 in those aged 30–39, 1·132 ± 0·101 g/cm^2 in those aged 40–49, 1·101 ± 0·119 g/cm^2 in those aged 50–59, 1·091 ± 0·157 g/cm^2 in those aged 60–69, and 0·970 ± 0·162 g/cm^2 in those aged 70–79 years of age or older. Using their data, we defined below mean BMD-2SD in each age decade or the presence of lumbar compression fractures as indicating osteoporosis and defined above mean BMD-2SD in each decade as indicating non-osteoporosis. Osteoporosis was defined as a BMD-2SD or more below the normal mean BMD (relative to age) or the presence of lumbar compression fractures. The cut-off values of osteoporosis measured at the lumbar vertebrae were 0.930 g/cm^2 in the 40s, 0·863 g/cm^2 in the 50s, 0·777 g/cm^2 in the 60s, and 0·646 g/cm^2 in the 70s or older.

HORMONES AND OTHER PROFILES

Serum concentrations of free testosterone, oestradiol, 1,25$(OH)_2$D, and high-sensitivity PTH (HS-PTH)[18] were measured by radioimmunoassay (RIA). Urinary Pyr and Dpyr concentrations were measured by high-performance liquid chromatography (HPLC)[19] in selected patients (Pyr and Dpyr: 25 patients with osteoporosis and 33 without osteoporosis), and serum OC was measured by immunoradiometric assay (IRMA) in 55 patients (25 with osteoporosis and 30 without osteoporosis). The values of urinary Pyr and Dpyr in urine samples are expressed per mol of urinary creatinine. All samples were measured with commercial kits (SRL Inc., Tokyo, Japan). Non-fasting blood was drawn between 0900 and 1100 h, and the plasma was removed and stored at −70°C until assay. Intra-assay coefficients of variation determined at our laboratory are 2·22% Pyr, 3·50% Dpyr, 3·84% OC, 2·69% 1,25$[OH]_2$D, 6·95% HS-PTH, 4·23% FT and 4·73% E_2. Inter-assay coefficients of variation specified by the manufacturer 2·35–3·83% Pyr, 4·23–5·96% Dpyr, 5·05–8·97% osteocalcin, 3·29–5·31% 1,25$[OH]_2$D, 10·2–12·6% HS-PTH, 6·63–18·90% free testosterone and 2·32–6·10% oestradiol.

STATISTICAL ANALYSIS

Statistical analyses were performed with the StatView package, version 5.0 (SAS Insitute, Cary, NC, USA) on an Apple Macintosh computer. All values are expressed as means ± SD unless otherwise indicated. Differences between groups were analysed by Mann–Whitney *U*-test (two groups) and Kruskal–Wallis test (three groups). Relations between pairs of variables were analysed by Spearman rank correlation. P values < 0.05 were considered statistically significant.

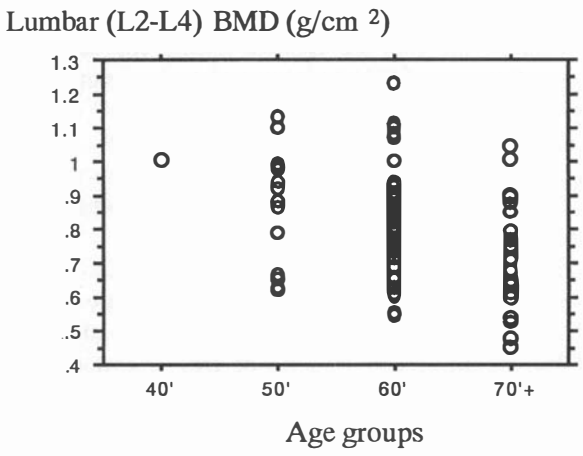

Figure 1. Bone mineral densities in each decade.

Results

Four men had lumbar compression fractures. Bone mineral density of the osteoporosis group ($n = 37$) was 0·663 ± 0·094 g/cm^2 and that of the non-osteoporosis group was 0·919 ± 0·129/ g/cm^2 ($n = 49$).

Mean BMD was not significantly different in any age decade (Figure 1). The means ± SD for all measured values in both groups are listed in Table 1. Age matching was done in the two

Table 1. Biochemical data for the osteoporosis and non-osteoporosis groups. BMI = body mass index; Pyr = pyridinoline; Dpyr = deoxypyridinoline; 1,25 $(OH)_2D$ = 1,25-dihydroxyvitamin D; HS-PTH = high sensitivity of parathyroid hormone; FT = free testosterone; E_2 = oestradiol

	Osteoporosis ($n = 37$)	Non-osteoporosis ($n = 49$)
Mean age (years)	65·8 ± 5·7	65·3 ± 7·7
BMI (kg/m^2)	25·1 ± 3·2	24·5 ± 3·9
Pyr (μmol/mol creatinine)	29·1 ± 8·7 ($n = 25$)	22·4 ± 6·8** ($n = 33$)
Dpyr (μmol/mol creatinine)	5·5 ± 1·7 ($n = 25$)	4·2 ± 1·6** ($n = 33$)
Osteocalcin (ng/ml)	7·96 ± 3·60 ($n = 25$)	5·48 ± 2·22** ($n = 30$)
1,25 $(OH)_2D$ (pg/ml)	38·3 ± 14·6 ($n = 32$)	40·0 ± 13·0 ($n = 45$)
HS-PTH (pg/ml)	335·3 ± 136·4 ($n = 32$)	333·3 ± 91·1 ($n = 39$)
FT (pg/ml)	3·92 ± 4·01 ($n = 37$)	6·99 ± 4·83** ($n = 47$)
E_2 (pg/ml)	13·83 ± 6·14 ($n = 33$)	17·40 ± 9·20* ($n = 45$)

Relative to osteoporosis: *$P < 0·05$, **$P < 0·01$.

groups. The urinary concentrations of Pyr and Dpyr were significantly higher in the osteoporosis group than in the non-osteoporosis group (pyridinoline: $P < 0{\cdot}01$, deoxypyridinoline: $P < 0{\cdot}01$) (Figure 2a,b). To minimize the urine sampling error, all data were corrected for urinary creatinine. The serum concentration of OC was significantly higher in the osteoporosis group than in the non-osteoporosis group ($P < 0{\cdot}01$). (Figure 2c). Since serum concentrations of OC are cleared by the kidney and serum concentrations can be influenced by renal function, we measured creatinine and confirmed that indices of renal function did not affect serum concentrations of OC.

Serum concentrations of $1,25(OH)_2D$ and HS-PTH were also not significantly different between the groups and were almost the same as the laboratory preference ranges. Serum concentrations of $1,25(OH)_2D$ were negatively correlated with HS-PTH concentrations ($r = -0{\cdot}247$, $P < 0{\cdot}05$). Serum concentrations of free testosterone and oestradiol were signficantly higher in the non-osteoporosis group than in those with osteoporosis (FT: $P < 0{\cdot}01$, oestradiol: $P < 0{\cdot}05$).

Discussion

Determining how osteoporosis develops in men with leprosy may provide useful information about osteoporosis in general. In our present study, the mean BMDs were below normal in each age group and showed no significant difference between patients in their 50s, 60s and 70s or older. BMD varied widely within each decade. This suggests that some factor other than ageing regulates bone volume in men with leprosy. We concluded previously that hypogonadism was an important factor.

Patients with leprosy are often in their 70s in Japan, and our interest is in whether diminishing bone volume continues rapidly with ageing in patients with osteoporosis and hypogonadism. If high bone turnover continues, risk of bone fracture must increase, and femur fractures contribute to a high mortality in older men.

Urinary Pyr and Dpyr are markers of bone resorption, and serum OC indicates osteoblastic activity. During high bone turnover such as that observed in postmenopausal women, these markers elevate.[13,14] In our current study, urinary concentrations of Pyr and Dpyr showed significant differences between the two groups ($P < 0{\cdot}01$). The serum concentration of OC, a marker of bone formation, was significantly higher in the osteoporosis group than in the non-osteoporosis group ($P < 0{\cdot}01$). Elevated OC indicates that bone repair is increased possibly due to compensation mechanisms for increased bone loss. Although the amounts of Pyr, Dpyr and OC were not measured in all subjects, we believe our data indicate that high turnover and bone loss had been ongoing in the osteoporosis group. This situation may be similar to that of postmenopausal women. If this high turnover cannot be corrected, the risk of fracture associated with ageing is greater for osteoporotic men than for non-osteoporotic men.

What can correct this high turnover? In Japan, vitamin D and calcium replacement therapies have been used in older women and men. Because intestinal calcium absorption decreases with ageing due to vitamin D deficiency in women[20,21] and men,[20] hypovitaminosis D predisposes individuals to hip fractures.[22,23] In calcium homeostasis in women, Riggs *et al.*[24] reported that type I (postmenopausal) osteoporosis was associated with decreased production of $1,25(OH)_2D$ secondary to a decrease in PTH, which leads to decreased calcium absorption. In type II (senile) osteoporosis, decreased osteoblast function and impaired production of

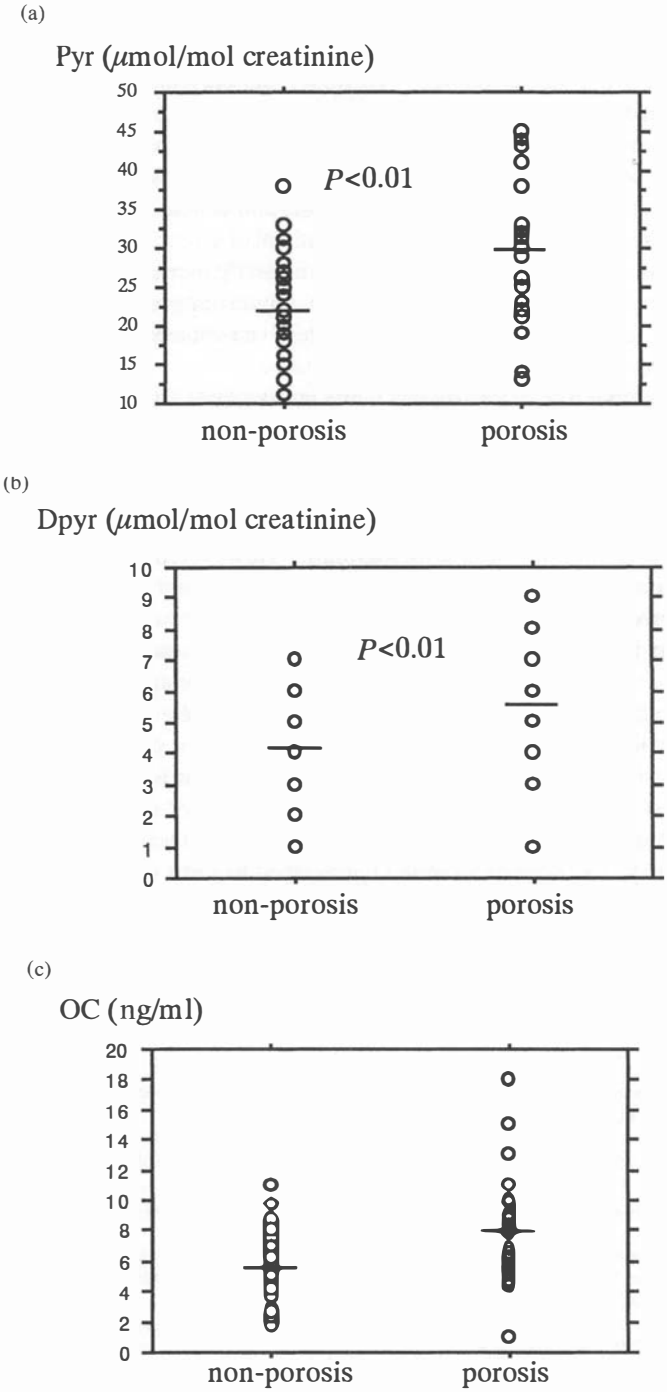

Figure 2. **(a)** Urinary pyridinoline concentrations in osteoporosis and non-osteoporosis groups. **(b)** Urinary deoxypyridinoline concentrations in osteoporosis and non-osteoporosis groups. **(c)** Osteocalcin concentrations in osteoporosis and non-osteoporosis groups.

$1,25(OH)_2D$ are primary, also leading to decreased calcium absorption and secondary hyperparathyroidism. In men, lower calcium absorption is reportedly associated with reduced plasma $1,25(OH)_2D$ concentrations.[2,25] However, our present results showed that $1,25(OH)_2D$ and HS-PTH had almost normal concentrations, with no significant differences between the osteoporosis and non-osteoporosis groups. Therefore, the administered dose of vitamin D was sufficient, and further replacement of vitamin D may not be effective. Jackson *et al.*[26] examined men with idiopathic or hypogonadal osteoporosis and concluded that when hypogonadal men with osteoporosis maintain abundant concentrations of vitamin D, their $1,25(OH)_2D$ synthesis remains normal, and bone remodeling is only modestly increased, which can be corrected by hormone therapy as in postmenopausal women. Given our present results, we agree with their idea. Hormone replacement therapy may be effective to correct bone turnover, even in elderly men.

The physiologial role of oestrogens in the human male has been reported. Two categories of oestrogen disorder have been noted: congenital absence or functional absence of oestrogens. Reports document an aromatase deficiency (aromatase cytochrome P450)[27–29] and an oestrogen-receptor defect.[30] In patients with aromatase deficiency, testosterone was normal[28] or high[27,29] and oestradiol was low.[27–29] In patients with oestrogen-receptor defect, testosterone was normal and oestradiol was high.[30] However, in our present data, concentrations of oestradiol and free testosterone were much lower than normal, and the low concentrations of oestradiol were correlated with those of free testosterone ($r = 0{\cdot}563$, $P < 0{\cdot}0001$). The hypogonadism in male leprosy patients is acquired (invasion of testes by *Mycobacterium leprae*) rather than congenital, and low concentrations of oestrogen may possibly be due to the decreased free testosterone rather than to impaired aromatization due to substrate deficiency for P450 aromatase. Which is dominant, testosterone or oestrogen, remains unclear.

In conclusion, in hypogonadal men with long-term leprosy, high bone turnover continues with ageing. We recommend clinical studies of treatment such as replacement therapy to determine appropriate measures to prevent bone loss and increasing risk of fractures in older men with leprosy. The dose of vitamin D prescribed to some of our patients seemed sufficient to prevent severe bone loss. We believe serum concentrations of FT regulate BMD. We postulate that hormone replacement therapy may be effective even in older men.

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Experiences from a collaborative project on the prevention of disability in leprosy patients in Shandong Province, the People's Republic of China

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Summary Shandong Province (present population 89 million) in the People's Republic of China established a leprosy control programme in 1955. Between that year and the end of 1999, allowing for death and migration, the cumulative number of cases registered was 53,618, including 120 cases on multiple drug therapy (MDT) and 18,248 who had completed satisfactory courses of dapsone monotherapy and/or MDT. Of this latter group, 9500 cases (52%) suffered from visible disabilities (grade 2 of the WHO classification). Prevalence and incidence rates of leprosy have decreased dramatically since 1955 and, on average, only 50–70 new cases are now being detected annually in the entire province. Leprosy is thus no longer a public health problem, but the existence of such a large number of patients with grade 2 disabilities is clearly a matter of serious concern. This paper describes a pilot project to investigate the potential of health personnel in the leprosy programme and the dermatology and sexually transmitted diseases services to (a) prevent deterioration of existing disabilities in ex-patients through self-care and (b) prevent new neuritis in patients on MDT through early detection and the use of steroids.

Introduction

Shandong Province (present population 89 million), in the People's Republic of China, is situated in the eastern, coastal part of the country. It has 17 prefectures and municipalities and 135 countries, with 80% of the population living in rural areas. With 573 people per square kilometre, it is one of the most densely populated provinces in the whole country.[1]

A leprosy control programme was established in 1955. Between that year and the end of 1999, allowing for deaths and migration, the cumulative number of cases registered was 53,618, including 120 cases on multiple drug therapy (MDT), as recommended by the World Health Organisation (WHO) and 18,248 who had completed satisfactory courses of dapsone monotherapy and/or MDT. Of the latter group, 9500 (52%) suffered from visible disabilities

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(grade 2 on the WHO classification). The prevalence rate of leprosy in Shandong decreased from 0.4 per 1000 of the population in 1967 to 0.0037 per 1000 in 1994 and the yearly detection rate decreased from 0.1 per 1000 in the period 1955–1959 to 0.066 per 1000 in 1990–1994. On average, only 50–70 new cases have been detected yearly in the entire province during the past decade. Leprosy is thus no longer a public health problem, but the presence of nearly 20,000 ex-patients with grade 2 disability is clearly a matter of serious concern.

Further details of the epidemiological situation in this province from 1955 to 1983 have already been published.[2] This paper describes a pilot project, in collaboration with The Leprosy Mission International (TLMI) and the Ministry of Health, China,[3] to investigate the potential of health personnel working with the leprosy control programme and the dermatology and sexually transmitted diseases services to (a) prevent deterioration of existing disabilities in ex-patients through self-care and (b) prevent new neuritis in patients on MDT through early detection and the use of steroids.

Materials and methods

The project aimed to:

1. Improve and complete the rehabilitation management and supervision system in preparation for a future provincial project.
2. Monitor and treat any new neuritis cases with a standard steroid regimen.
3. Prevent or control the occurrence of new disability and deformity over 3 years as follows:
   a. Prevent any further loss of sensation or strength after diagnosis and to reverse loss occurring within 6 months prior to diagnosis, by improving early detection and treatment of neuritis.
   b. Reduce the prevalence of wounds and open cracks by 80% and control the incidence of new re-occurrence to below 5% for outpatients and below 2% for inpatients.
   c. Prevent any increase in vision loss, joint stiffness and bone loss following nerve dysfunction.
4. Minimize the social and functional effect of the above impairments on the lives of patients and their families.
5. Provide protective footwear for more than 80% of cases with insensitive feet in the pilot areas within 1 year of starting the project.
6. Enable diagnosed cases in the project areas to be trained in self-care and to achieve proficiency in 60% of them by the end of the project.

Project approval was granted by the Provincial Bureau of Health, with emphasis on the following principles:

1. Main attention and priority to be given to patients under 60 years of age.
2. Strong government commitment and community participation.
3. A combined approach between the specialized leprosy services and the primary health care services.
4. Strengthening of empowerment of disabled patients and their families.

IMPLEMENTATION

After an initial national meeting, contracts were signed between the director of the Provincial Bureau of Health and the directors of the bureau of health in the six selected pilot counties, in

order to strengthen leadership and ensure allocation of funds on time. This was followed by a provincial meeting to motivate and ensure the participation of health staff in general health services at different levels. The main activities in the implementation of the project were as follows:

Training

In general, training involved affected persons, leprosy doctors, village doctors and other paramedical health workers in the main principles of disability management, focusing on simple measures that can be carried out in the home and field situation. At the beginning of the project, a workshop on prevention of disability (POD) in terms of technical and management aspects was held by the national leprosy control centre (CLC) and experts from TLMI for leprosy control managers in charge of the project at the provincial level, followed by a similar training course at provincial level. Leprosy workers in charge of the project at county level participated in the workshop. Paramedical health workers at township level and village doctors, in turn, were trained in a 1-day course organized by local health authorities at county level.

Technical aspects of the project in the field

General description of activities. According to the guidelines of the project and after training of health staff at different levels, project staff in leprosy control stations visited the homes of the patients. During the visits, primary and secondary impairments of the patients were assessed and recorded on project forms (information at baseline). Health education on self-care was then given according to each patient's individual problems, and patients were told how to take care of their hands and feet in their everyday lives, with regard to numbness and deformity. Care of the eye and management of cracks and wounds in the hands and feet at home was discussed and demonstrated. Some drugs such as eye ointment and drops, materials such as bandages, scalpels, tapes and dark eye glasses, were provided and replaced according to needs. The persons involved were also told to consult rural doctors or paramedical doctors in township hospitals for any problems they could not deal with at home.

Methods of testing muscle strength and sensation of hands and feet. The methods of testing muscle strength and sensation of hands and feet were the same as those used in the project state 1, as already described.[3,4] Briefly, a three-scale system was used in testing muscle strength dominated by ulnar nerve, radial nerve, medial nerve and popliteal nerve, respectively (normal = 0, limitation of movement range = 1, reduction of resistance = 2, paralysed = 3). Ten points on each hand or foot were tested with a ball-pen. The results of the tests were marked in a standard chart at baseline and during follow-up for comparison.

Supervision and evaluation

The project had full supervision from provincial to county level, in a scheduled manner (twice a year), with or without assistance of experts from CLC and TLMI. Ongoing training was conducted during supervision by the project management team, consisting of experts from TLMI, CLC and Shandong Provincial Institute of Dermatology and Venereology evaluated the results of the project in three of the six pilot counties.

Table 1. Baseline profile of 1132 cases affected by leprosy, by sex, leprosy type, age group and residence in six pilot counties in Shandong

	Sex		Leprosy type		Age group			
Residence	Male	Female	MB	PB	< 40	< 50	< 60	> 60
Out-patients	854	213	427	640	33	130	422	482
In-patients	64	1	42	23	4	3	15	43
Total	918	214	469	663	37	133	437	525

Results

One thousand and eighty-six of the 1132 cases involved in the project form a cohort of persons both at project start and at the latest review (32 had died and 14 were lost). Table 1 illustrates the sex, leprosy type, residence and decades of birth of persons in this group. The primary nerve function impairment among 1086 leprosy cases at the start of the project is given in Figure 1. One of the objectives of the project had been to make patients competent in self-care, but due to lack of a clear definition and proper indicators, this proved difficult to measure. Similarly, it was difficult to assess the social effect of the project on lives of the leprosy-affected persons and their families.

Regarding nerve function impairment (NFI) monitoring in the group of active cases, three out of 54 cases on MDT were identified as having neuritis. After 6 months treatment with a standard regimen of steroids, one of the three was considered as partly recovered and the other two as showing no change. The number in this cohort of patients was obviously too small to be significant. Figure 2 illustrates the changes in secondary impairments over time in the period of the 3-year project.

Vision loss and bone loss in this group of patients were 399 (160 eyes and 239 bones, respectively). Since vision loss (due to a variety of inflammatory conditions) and bone loss did not show much change, they are not illustrated here in detail.

In summary, the main outcome with regard to secondary impairments included the following (Figure 2):

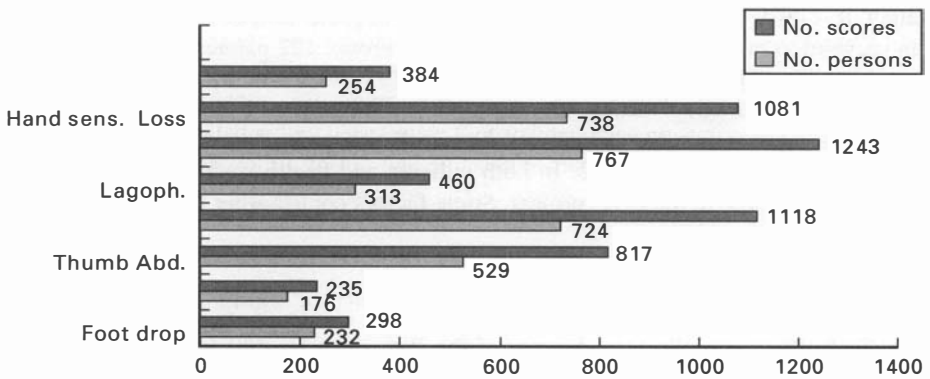

Figure 1. Primary nerve function impairment among 1086 leprosy cases at the start of the project.

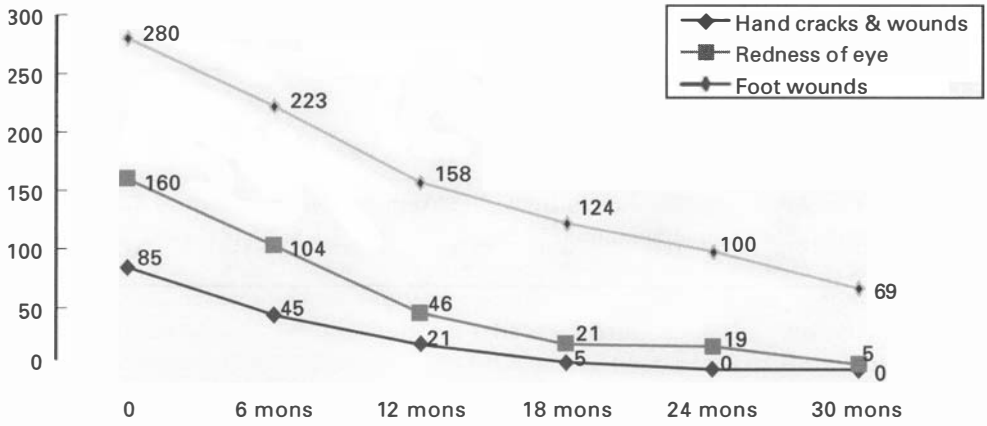

Figure 2. Changes in secondary impairments over time among 1086 leprosy cases in the 3-year period of the project.

1. A 97% reduction in number of patients with redness of the eyes, with loss of corneal sensation or lagophthalmos.
2. A 94% reduction in number of persons having open cracks and wounds on their hands.
3. A 75% reduction in number of sole wounds in feet with sensory loss.

Discussion

With regard to the early detection and treatment of neuritis with steroids, only 54 active cases were monitored in the period of the project and only three of them identified as having new neuritis. After treatment with steroids for 6 months, one patient with obvious nerve pain and sensory loss in the sole completely recovered, but there was no change in the other two. Obviously, the number of cases with new neuritis was too small to make any assessment. The results of treatment of neuritis with steroids nationwide, however, have been impressive, and comparable to studies in other parts of the world.[5]

Protective footwear, even sports shoes sold in the market, has a definite role in the protection of feet with sensation loss,[6,7] if used properly. Five hundred and six cases received footwear in this group. Due to the lack of a control group, however, and the short duration of the study, it is difficult to assess the role of footwear in protection of feet with sensation loss and in prevention of relapses of foot wounds. In this group, 122 pateients with plantar ulcers achieved healing within 1 year of the project, and 75% reduction within the 3-year period, which is more encouraging than results reported in the literature from other countries.

The most impressive achievement was the remarkable reduction in number of secondary impairments, as shown in Figure 2. In both patients and health staff, this led to a marked increase of confidence in the POD project. Some factors contributing to this achievement of the project are outlined below.

STRONG GOVERNMENT COMMITMENT AND INVOLVEMENT OF GENERAL HEALTH SERVICES

- A medical officer (usually vice-director of the Bureau of Health) was appointed to be in charge of the project at three levels (province, prefecture and county). This made co-ordination and supervision much easier.

- A series of documents on the implementation of the project were issued at the above three levels.
- Contributory funding was allocated on time.

EMPHASIS ON TRAINING

Since a POD project is totally different from a programme aiming to control the spread of the disease, including implementation of MDT, training of staff involved at different levels, not only in workshops but also in ongoing POD activities, is crucial to success. During the project period, considerable effort was made not only for training in knowledge and skills, but also to develop correct attitudes towards leprosy-affected persons. In this context, foreign experts set a good example for our staff both in the training courses and during field visits.

AN ACTION LEARNING MANAGEMENT APPROACH

The 'action learning' management approach encourages involvement of teams of people, in this case leprosy staff, so that they focus on the same or similar objectives, meeting together periodically to encourage and learn from each other and to exchange ideas and reports regarding progress.

SOME LESSONS LEARNT FROM THE PROJECT

Planning

Affected persons and their family members, integrated programme staff, and the project managers might be more closely involved in all stages of planning and implementation of a POD project of this kind.

Case selection priorities need to be clarified

Several problems were encountered with regard to selection of project cases. This was partly because the selection guidelines were insufficiently clear and partly because numbers to be involved were based on WHO disability grading alone. The grading does not give sufficient detail for POD planning purposes. It is important that future surveys for this purpose provide more information regarding the type and extent of impairment. Informal questionnaires may be used to identify the patients' felt needs and the relationship between impairment and these needs.

Communication skills

There are many good reasons why a client may not implement advice given. For example, he/she may not be convinced of the reasoning behind the advice, or may lack access to ongoing supplies of materials or may find it impractical to follow the advice in a given situation. Ongoing training is needed so that staff are equipped with listening, problem identification and problem-solving skills, and do not advise too much and listen too little.

Sustainability

Sustainability of the project is the key for the benefit of patients in the long run, and one of the main objectives of this project. On its completion, it is clearly essential that patients have the motivation, knowledge and ability to continue self-care and other activities on a long-term, often indefinite basis. Unfortunately, it has not been possible to address this issue adequately so far in this province, and there is a need to consider an overall plan, perhaps combining self-care with community-based rehabilitation, so that the full potential of the approach described in this paper becomes truly sustainable.

CONCLUSIONS

1. Although the project described here did not succeed in all its initial objectives, it confirmed, to a remarkable degree, previous reports[3,5] of the potential of health staff to prevent and reverse secondary impairments in patients affected by leprosy, notably red eyes, cracks and wounds of the hands and feet.
2. The results achieved so far should not be regarded as short-term or dependent on external aid and encouragement, but rather become accepted practice by the patients and staff concerned, with a high degree of sustainability.
3. The good results recorded were evident to both health staff and patients and contributed greatly to increasing confidence in the value of the methods used. It is intended that they will form the basis for POD and rehabilitation acitivities in the entire province in the future.

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We wish to record our thanks to the Leprosy Mission International (TLMI) and other donors for their financial support for this 3-year pilot project. We also thank Miss Jean Watson, Miss Angelika Piefer and others involved in the project for their technical guidance and care for our patients during and after the project in Shandong Province. We are extremely grateful to all the staff involved in this project for their hard work and kindness to so many patients disabled by this disease.

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A high incidence of viable *Mycobacterium leprae* in post-MDT recurrent lesions in tuberculoid leprosy patients

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Introduction

The differentiation between relapse and late reversal reaction in post-MDT recurrent lesions in paucibacillary cases of leprosy is difficult under field conditions.[1] Even histopathological studies are of limited use.[2] Therefore, a therapeutic course of corticosteroid is recommended[3] and is used in practice particularly in tuberculoid (paucibacillary) cases presenting with fresh activity in old and/or appearance of new lesions after release from treatment. This is based on the assumption that a delayed hypersensitivity type reaction to persisting dead bacterial products (antigen), causes late reversal reaction. The present study was carried out to determine whether viable bacteria are present in recurrent lesions of tuberculoid and borderline tuberculoid leprosy cases. The type and activity of the lesions are assessed histopathologically. The results obtained in a small group of 25 patients are presented in this paper.

Material and methods

Twenty-five skin lesional biopsies obtained from 25 cases of borderline tuberculoid (BT) leprosy referred to the Foundation between 1996 to 1998 and presenting with recurrent lesions 1–13 years after the release from treatment were studied histopathologically and also tested for the presence of viable bacteria, using the standard mouse foot pad method. Only confirmed cases of tuberculoid leprosy with reliable treatment and follow up details were included in this study. For each patient, a detailed history was taken, including pretreatment presenting symptoms, treatment details, reactions if any, followed by a clinical charting to record the old and the new skin lesions as well as nerve lesions. Skin smears and lepromin testing were also done. A deep incision skin lesional biopsy was obtained from an active lesion, using local anaesthesia.

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0305-7518/01/072337+08 $1.00

Part of each skin biopsy was fixed in formal Zenker and embedded in paraffin. Five micron thick sections stained with Trichrome modified Fite Farraco (TRIFF) were used for determining the classification (as per the Ridley–Jopling classification),[4] type and extent of cellular infiltrate and presence of acid fast bacilli (AFB) if any, in the section. Another part of the biopsy was homogenized within 24 h and bacterial load per gram weight was determined using the standard protocol (WHO/CDS/Lep/86.4.1987).[5] The weight of the tissue available for homogenization ranged between 0·1 and 0·3 g. The final volume of the suspension was maintained at 1 ml per 0·1 g of tissue weight. The homogenate thus obtained, regardless of presence or absence of any AFB, was injected into both the hind foot pads (0·03 ml/foot pad and inocula size not exceeding 1×10^4 *M. leprae*), of a minimum of 10 Swiss white mice in each case. Foot pad harvests were carried out at 6, 7 and/or 8 and 12 months post-inoculation using Shepard's method.[5] In short, a known volume of foot pad tissue suspension was spread over the spot slide, fixed and stained. AFB were counted in a minimum of 200 microscopic fields/sample. The lower limit of detectability by this countering method is 1×10^4 *M. leprae*/ml. A minimum of two counts per foot pad were obtained at 6, 7 and 8 months. All the remaining mice were harvested at the 12th month.

DEFINITION OF SIGNIFICANT GROWTH IN THE FOOT PADS OF NORMAL S/W MICE

One or more per foot pad counts showing $\geq 1 \times 10^5$ *M. leprae* in the harvests carried out at the 6th month or later (WHO/CDS/LEP/86.4,1987).[5]

RESULTS

Clinical findings

All 25 cases in this study were smear negative, lepromin positive and clinically presented with borderline tuberculoid (BT-TT) type of leprosy at the time of recurrence of lesions. All had presented with at least one impaired nerve (mostly sensory) and one or more skin lesions (maximum five). None of the cases had overt clinical signs of type 1 reaction. In most cases the recurrent skin lesion/s were mildly erythematous. Their pretreatment classification was also on the tuberculoid end of the spectrum, viz. TT-BT. The duration of treatment varied from 6 months to 3 years. All except five cases were treated with two drugs, viz. DDS 100 mg daily and RFP 600 mg monthly. In five cases, CLF was added later apparently for persisting neuritis. Fifteen (60%) had received a therapeutic course of corticosteroid during or after release from treatment (see Table 1).

HISTOPATHOLOGY

Thirteen biopsies showed features characteristic of active BT leprosy, viz. the presence of granulomatous infiltrate consisting of epithelioid cells and Langerhans type of giant cells surrounded by lymphocytes (see Figure 1a,b). Two biopsies had a few AFB (1+) in the TRIFF stained sections. Thus, both clinical and histopathological evidence was suggestive of BT reactivation/relapse. The remaining 12 lesions studied showed features of type I reaction, viz. increase in intra- and extracellular oedema, fibroblast proliferation, increased

vascularity along with epithelioid cell granuloma (see Figure 2a,b). A few AFB (1+) were seen in one of these lesions (see Table 1).

BACTERIAL LOAD AND THE VIABILITY TEST RESULTS (TABLE 1)

Of the 13 biopsies that had shown active BT pathology, only two cases were a few AFB were noted in the homogenate. The bacterial loads were 7 and 3×10^5/g wt. In the others no AFB were observed in 200 microscopic fields. Nevertheless, five of the inocula showed over 10-fold growth in the foot pad, (this includes one of the two cases that showed AFB in the section as well as homogenate) thus viable bacteria were detected in 5/13 relapsed BT cases (38·5%).

Of the 12 biopsies that had features of reversal reaction, one had AFB in the homogenate. Seven of the inocula showed significant growth in the foot pad; thus viable bacteria were detected in 7/12 reactional BT lesions (58·3%).

Although the slit skin smears were negative in all 25 patients, the homogenate showed AFB in three cases and viable bacteria were detected using the mouse foot pad technique in 12 lesions.

Discussion

The present study looked for viable mycobacteria in post-MDT recurrent lesions in borderline tuberculoid leprosy. Viable mycobacteria were detected in 48% of the recurrent lesions in this borderline tuberculoid group of patients, despite the lower limit of detection sensitivity being 1×10^4/ml in the system used. This implies that the occurrence of viable bacteria in tuberculoid lesions is fairly common. Interestingly the incidence of viable bacteria in lesions showing histopathological evidence of reaction was higher than that of the non-reactional lesions. Therefore, it can be deduced that these reversal reactional lesions are probably relapses presenting with reaction. In retrospect, the presence of a growing bacterial focus could be playing a crucial role in triggering the reaction. Fifteen of the cases in the present study, before the biopsy, had received a therapeutic course of steroid during and/or after release from treatment or on recurrence of lesions. It would be premature to comment on whether the use of corticosteroid had any role to play in promoting the survival of *M. leprae*, but results obtained in the present study suggest that a more systematic study should be undertaken. The WHO control studies report that in PB cases 32·9% of relapse occur during the first year, 34·1% of relapse during the second year and 16·5% of relapse during the third year. Thus the majority of relapse (83·5%) occurred during the first three years of release from treatment.[6] It is noteworthy that seven of the relapses in this series occurred 5–13 years after the release from treatment and five of them had viable mycobacteria in the foot pad testing. Persistence of solidly stained osmiophylic bacilli in the peripheral nerve were recorded through electron microscope, in 31% of BT cases long after stopping the treatment.[7] These findings suggest that even in PB patients, reactivation of the disease due to persisters occur as late as 5–13 years after the release from treatment.

In the present study, the mouse foot pad results were interpreted applying the criteria given by the WHO/CDS/LEP/86.4 1987 report. We have shown that, using foot pads of

Table 1. Summary of clinical and bacteriological findings in 25 recurrent BT lesions. RFT, release from treatment, MFP, mouse foot pad; PB-MDT, DDS + RFP; MB-MDT, DDS + RFP + CLF; (+S) patients who had received therapeutic course of corticosteroid

Case no.	Details of patients/ relatives	RFT duration in years	Histopathology	Bacterial load/g wt	Viability in MFP (count $\times 10^4$/foot pad)		
1	BK/67 F PB-MDT × 3 years	7	BT granuloma	0	6th 7th 12th	0 0 147, 33, 28, 1·3, 0, 0	0 0
2	JV/51 M PB-MDT × 2 years (+S)	2	BT granuloma (+RR)	0	6th 7th 12th	0 0 0/6	0 0
3	KBD/50 M PB-MDT × 3 years (+S)	2	BT granuloma	0	6th 7th 12th	0 0 0/4	0 0
4	SV/47 F PB-MDT × 1 year (+S)	2	BT granuloma	0	6th 7th 12th	0 0 0/5	0 0
5	HD/32 M PB-MDT × 2 years (+S)	9	BT granuloma (+RR)	0	6ht 7th 12th	0 0 135, 134, 133	0 0
6	KS/16 F PB-MDT × 1 year (+S)	2	BT granuloma (+RR)	0	6th 7th 12th	0 0 0/4	0 0
7	TS/41 F MB-MDT × 7 months (+S)	3·7	BT granuloma (+RR)	0	6th 7th 12th	0 27 0/4	0 0
8	AP/38 F PB-MDT × 3 years (+S)	3	BT granuloma (+RR)	0	6th 8th 12th	0 13 0/4	0 0
9	PS/25 M MB-MDT × 3 years (+S)	9	BT granuloma	0	6th 7th 12th	14 0 0/4	4·0 0
10	DH/35 M PB-MDT × 2 years (+S)	10	BT granuloma	0	6th 7th 12th	0 0 227, 18, 411, 197, 49, 12, 96, 0	0 0
11	ST/28 M MB-MDT × 2 years (+S)	3	BT granuloma	0	6th 7th 12th	0 0 0/5	0 0
12	PK/30 F PB-MDT × 1 year MB-MDT × 2 years (+S)	1	BT granuloma (+RR)	0	6th 7th 12th	0·7 0 0/4	0 0

normal Swiss White mice, it was possible to obtain a significant fold increase in 12/25 inocula that apparently contained less than 1×10^4 *M. leprae* per ml of tissue homogenate (0·1 g of tissue). It is important to note that in all except four cases, a significant fold increase in the foot pad was obtained only at the 12th month. A similar delay in growth in the foot pads of normal mice was recorded by us in two cases of secondary drug resistance.[8]

Table 1. Continued

Case no.	Details of patients/ relatives	RFT duration in years	Histopathology	Bacterial load/g wt	Viability in MFP (count×10^4/foot pad)		
13	SK/35 F PB-MDT × 6 months (+S)	1·9	BT granuloma	3 × 105	6th 7th 12th	0 0 0/5	0 0
14	GR/39 M PB-MDT × 6 months	2·5	BT granuloma (+RR)	7×10^5	6th 7th 12th	0 0 139, 65, 147, 111	0 0
15	PG/58 M PB-MDT × 1 year (+S)	2	BT granuloma (+RR)	0	6th 7th 12th	0 27·5 0/4	0 0
16	SM/28 M PB-MDT × 6 months	5	BT granuloma	0	6th 7th 12th	0 0 0/5	0 0
17	GK/14 F PB-MDT × 6 months	6	BT granuloma	0	6th 7th 12th	0 0 0/4	0 0
18	KV/48 M PB-MDT × 6 months	2	BT granuloma (+RR)	0	6th 7th 12th	0 0 0/6	0 0
19	UK/40 F PB-MDT × 10 months	1	BT granuloma	0	6th 7th 12th	0 0 0/6	0 0
20	GR/14 F PB-MDT × 6 months	3	BT granuloma	0	6th 7th 12th	0 0 0/5	0 0
21	YT/18 M PB-MDT × 6 months (+S)	2·3	BT granuloma (+RR)	0	6th 7th 12th	0 0 47, 0, 0, 0	0 0
22	IN/19 F PB-MDT × 18 months	2	BT granuloma	0	6th 7th 12th	0 0 1·4, 4, 8, 14, 1·4, 2·7, 0, 0·6	0 0
23	DB/15 M PB-MDT × 1 year	6	BT granuloma	7×10^5	6th 7th 12th	2·3 1 11, 1, 0, 0, 0	0 0
24	YP/21 M PB-MDT 6 months (+S)	2	BT granuloma (+RR)	0	6th 7th 12th	0 0 0/4	0 0
25	PK/32 M MB-MDT × 2 years	13	BT granuloma (+RR)	0	6th 7th 12th	0 0 4·8, 32·6, 115, 3, 3, 37, 66	0 0

In the present series, in four cases *M. leprae* fold increase was noted at one of the earlier intervals but not at the 12-month harvest. Known contributory factors to such inconsistent results are subminimal number of bacteria in the inocula, tendency of *M. leprae* to clump and loss of inocula due to dissemination.[9] Our findings reiterates the importance of carrying out regular foot pad harvests and extending at least up to the 12th month besides proving that the foot pads of the normal Swiss white mice could serve as a good, more importantly

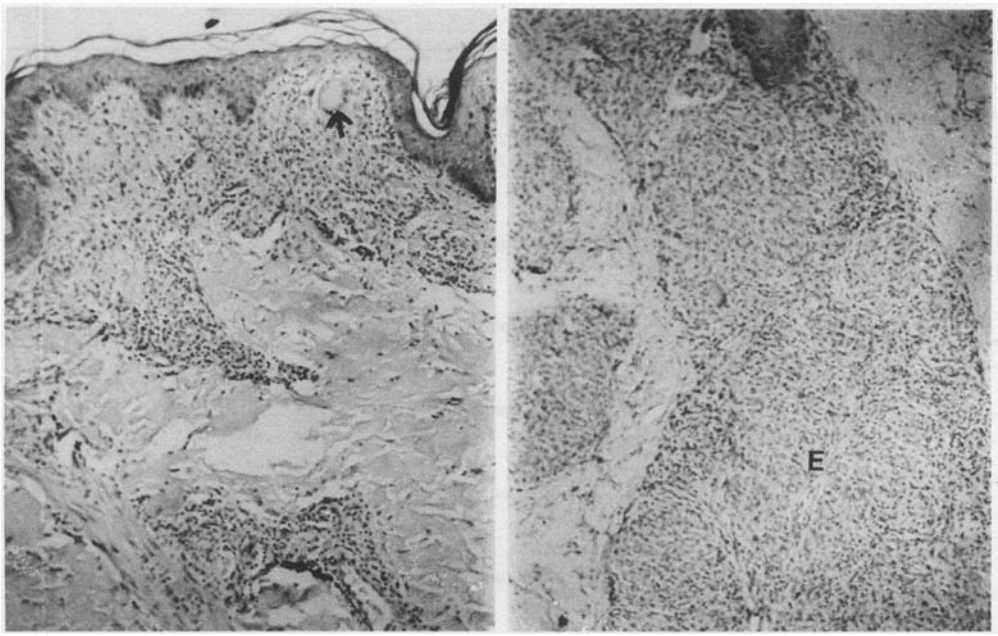

Figure 1. a Characteristic borderline tuberculoid type of infiltrate consisting of epithelioid cells, Langerhans giant cells (arrow) and lymphocyetes are seen in the superficial dermis in a relapsed BT patient (case 10). TRIFF stained section. Magnification × 150. **b** Similar large granulomatous infiltrate (I) is seen coursing along the hair folicle in the mid dermis, in the above lesion. Magnification × 150.

a specific and a time tested system that allows the expansion of an inocula containing less than 1×10^4 organisms. The time taken indeed is a major disadvantage. The quicker molecular based technique such as RNA based polymerase chain reaction detection system could be desirable under these circumstances provided a proper concordance is established.[10]

In summary, a total of 25 skin lesional biopsies obtained from 25 borderline tuberculoid cases of leprosy, presenting with recurrence of lesions 1–13 years after the release from MDT were studied using histopathology. They were also tested for the presence of viable *M. leprae* using the mouse foot pad method. Forty-eight percent (12/25) of the biopsies showed presence of viable *M. leprae* as determined by the significant growth ($>1 \times 10^5$/ foot pad) in the foot pads of normal Swiss white mice. The incidence of viable *M. leprae* in the lesions that showed histopathological evidence of reversal reaction (RR), viz. 7/12 (58%) was higher than the ones with no evidence of RR (5/13 = 38·5%). These findings have far reaching implications in the management of such cases.

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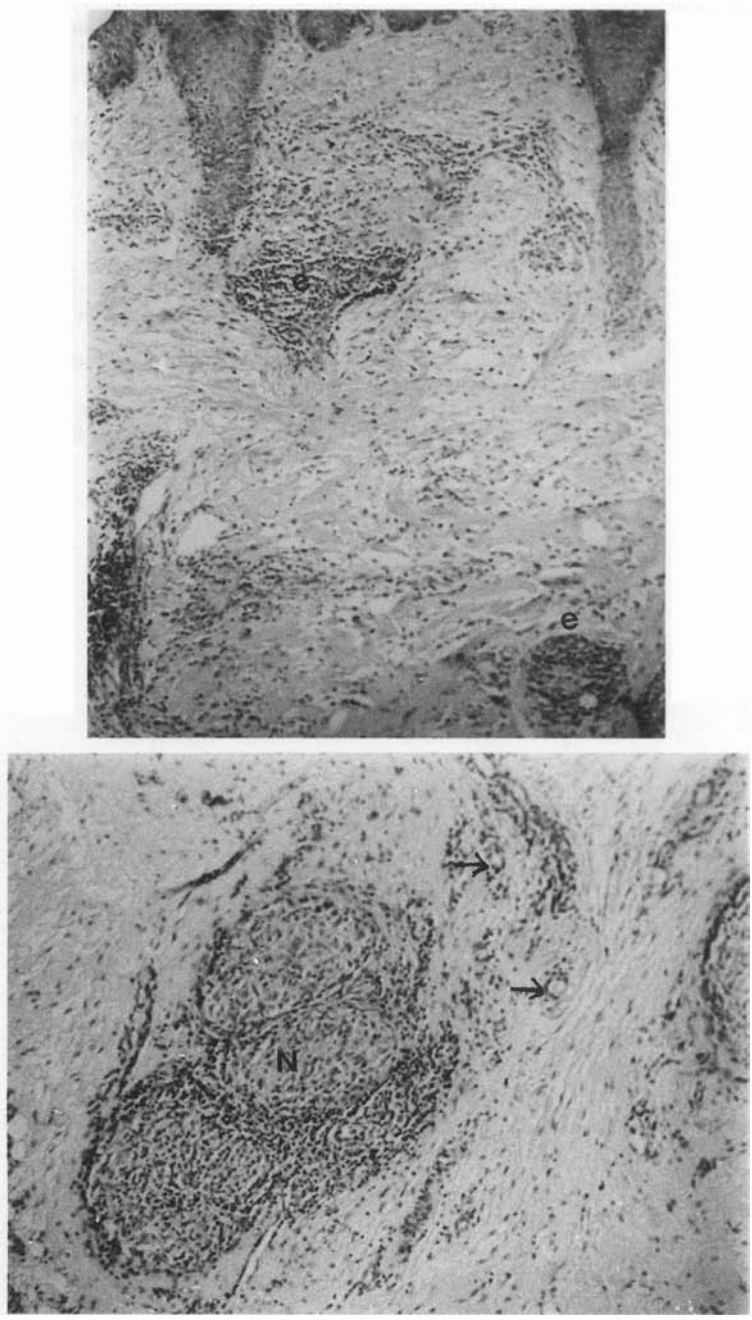

Figure 2. a A characteristic early type 1 reaction in a BT lesion (case 5). Note the presence of epithelioid cell foci (e) and proliferation of fibroblasts on an oedematous background in the superficial dermis. TRIFF stained section. Magnification × 150. **b** In the same lesion (**a**) infiltrated and oedematous dermal nerves (N) are seen in the deeper dermis. Note the proliferation of fibroblasts and blood vessels (arrow). Magnification × 150.

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FURTHER EDUCATION SERIES

HIV/AIDS testing and counselling

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The need for HIV testing: clinical, surveillance, research

In some parts of the world the human immunodeficiency virus and the acquired immune deficiency syndrome (HIV/AIDS) has become the most common in-patient diagnosis amongst both adults and children. Many countries, although till now relatively spared, are likely to see a huge increase in prevalence of infection and manifestation of disease over the next few years. The daily clinical practice of health care workers (HCWs) will therefore be affected by the necessity to be familiar with the diagnosis of HIV-related conditions and by situations in which they feel it would be beneficial for an individual to know his or her HIV status. The individual may be healthy or may be suffering from what could be an HIV-related disease. HCWs may also be approached by individuals, healthy or sick, asking for HIV testing. Reasons for seeking an HIV test vary and may include concerns over current state of health, concerns over high-risk behaviour (long standing or a particular event), or marriage plans.[1] The HCW should thus be equipped with the skills to counsel and to arrange an HIV test in a variety of circumstances.

HIV testing is a cornerstone to preventive strategies, as the knowledge of HIV status can have a profound effect on behaviour. Those already infected may change their behaviour in order to reduce transmission to others and those found negative may chamge their behaviour if they feel they have been given a second chance. Using testing to facilitate these changes in behaviour requires effective counselling and provision of support to implement strategies to reduce risk, such as the use of condoms, and the provision of additional information on safer sex and ongoing counselling.

HIV testing may also be performed for surveillance or clinical research purposes. HIV testing in this context is a very sensitive issue. For surveillance it is most commonly done anonymously. For example, in programmes where HIV sero-prevalence surveys are undertaken in the antenatal clinic, the testing is done on 'unlinked' anonymous samples, i.e. after

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all identifiers that can link a particular result to an individual have been removed. In many countries this is considered sufficiently protective of the individual to allow testing without consent as the result can never be traced back.

When people (usually patients) are tested for research purposes, it requires careful consideration to select a policy that fits the particular setting. Some research groups undertake 'informed consent without disclosure', i.e. they ask for consent to test the subject's sample, assure them of confidentiality and do not report the result to the subject. This is the most common in community studies on healthy individuals. Others counsel the subjects and report the results to them. In a research setting it is important to ensure that the individual will benefit from knowing their HIV status before selectting the latter policy. There therefore needs to be adequate access to support and post-test counselling and for those who are HIV positive, there needs to be access to a good standard of care.

HIV TESTING—HOW CAN IT BENEFIT THE INDIVIDUAL

Testing for antibody to HIV is different from many other clinical tests due to its social and ethical implications.[2] In medical terms there may be little that can be offered by way of treatment in the poorest parts of the world. In addition HIV is a stigmatizing infection, because of its association with sexual activity. It is difficult to predict an individual's prognosis and there are implications for the individual's sexual partners, their unborn children and their social situation. From this, it may seem that HIV testing holds little appeal for an individual, particularly if they suspect they may be found positive. On the other hand, they may realize that knowledge of their HIV status allows them to think and plan realistically for their future; making decisions in their life to maximize their health, making decisions on marriage, re-marriage or childbearing, and taking steps to avoid infecting other people. Importantly, whether testing is or is not desirable for an individual cannot be decided by another person, and the counselling process should enable them to come to an informed choice. People who suspect they may be HIV positive may also be reluctant to undergo testing due to concerns about stigmatization, reactions of relatives, or fears over breach of confidentiality.[3,4] Individuals may be more concerned about the social/support aspects of AIDS than about the medical aspects, and counsellors should appreciate this.[5]

HIV TESTING—THE SETTING

The setting in which HIV testing is offered will affect the willingness of individuals to seek testing. Specialized clinics and staff may offer a service that is more professional, but the target group may feel that attendance at such a clinic is itself stimgatizing compared with visiting a general health care facility. Different people are likely to prefer different environments for HIV counselling and testing,[6] and the availability of a variety of options is likely to maximize the uptake in the community. Different approaches to counselling may be used such as, group or couple or individual counselling, the appropriateness of each depending on the individual and their medical and social circumstances.

HIV TESTING—WHAT TEST TO USE

Many tests are available, and their description is not within the scope of this article. The most widely used tests do not identify the presence of the virus itself, but the antibody response to

the virus. Thus the antibody tests may be negative in early infection (prior to 'seroconversion') before the antibody has risen to a detectable level, or negative late in disease when the immune system has broken down to the extent when antibody production is no longer possible. The important thing is to know the limitations of the testing method employed, its reliability, and sensitivity and specificity. It may be appropriate to repeat positive tests if the individual has not tested positive previously. The test should also be appropriate for the region, as HIV-2 is prevalent in some communities and not in others. Many tests only identify HIV-1 infection. Some rapid tests are available that can be performed at the bedside or in the clinic for quick results but most are still done by laboratory assays requiring a qualified laboratory technician.

Counselling

As a general principle, all testing should be promoted with a view towards aftercare, with particular consideration to the availability of support services, drugs and condoms. The counsellor should have the facility to refer the individual where appropriate for treatment of sexually transmitted infections or tuberculosis, for psychological support and to self-help groups for people living with HIV or AIDS.

COUNSELLING—THE COUNSELLOR

People from a variety of backgrounds may become good counsellors. Many counsellors will be HCWs, drawn into it through their normal duties. Sometimes, however, other people may be more suitable particularly for special groups, such as youth or commercial sex workers. Factors such as age and gender and approachability should be taken into consideration, and peers or influential/respected members of the appropriate community may be appropriate.

HCWs may feel that they do not have enough time to counsel well or they may feel inadequately prepared or trained. There are, however, guidelines that can be followed, usually available from National AIDS control programmes or other organizations involved in HIV/AIDS within a country. It is important that all HCWs are aware of and have access to such materials.

A close knowledge and understanding of the community is required for effective counselling, but it may be difficult for someone to counsel within their own community. A counsellor may feel embarassed discussing sexual practices with friends and neighbours. In addition, the individual being counselled may feel that confidentiality is more likely to be breached if the counsellor is a member of their close community. Counselling by someone of the same sex is generally more comfortable for the individual.

It is important that those who direct Health Services recognize that the counsellors themselves need support in this difficult process. They need training and ongoing support to assist them in dealing with difficult situations. For example, situations may arise in which the counsellor feels that disclosure to other people is appropriate, either to spouses, relatives or medical staff. As a matter of principle, however, the individual being tested should have the right to choose with whom to share their results, and this should be respected. There may be a conflict in some countries where notification to authorities is a legal requirement in which case the counsellor will need to take this into account when helping the individual to decide

whether they wish to be tested. There are particular challenges when the event precipitating the need for testing involves rape or incest.

The counsellor should ensure that there is a rationale for testing in each case. It should not be done indiscriminately. A good rationale, whether it is the individual's wishes or clinical condition, will make the counselling easier.

PRE- AND POST-TEST COUNSELLING

Adequate 'pre-test counselling' is very important. The issues that should be covered in a pre-test counselling session are summarized in Box 1. Good pre-test counselling will assist the counsellor greatly when it comes to giving a result, as the individual will have been prepared for eventualities. Immediately after the result is given, there may be either great relief or distress. A prepared individual is likely to be able to absorb better what the counsellor is saying and to consider the advice later on.

Box 1. Pre-testing counselling checklist[7]

- Welcome
- Introductions
- Warming up
- Take time to get to know each other
- Reason for coming, and current symptoms if any
- Discuss confidentiality
- Relating current physical status to AIDS
- Determine present knowledge of HIV/AIDS
- Provide further information on HIV/AIDS, infection transmission and disease
- Discuss why testing is being considered
- Explore the meaning of possible results
- Risk assessment
- Shared confidentiality (third person)
- Obtaining informed consent for the test
- Check if individual wants to know results
- Cover technical aspects of testing
- Inform about waiting period
- Determine who will be involved
- Do a complete needs-assessment and resource-assessment of individual
- Summary
- Date of next appointment

Counselling is an opportunity for education, but it should not be a lecture. Counselling should be culturally appropriate, non-judgmental, take place in privacy and it should be relevant to the individual. It should be appropriate to their educational level. The counsellor should be familiar with local terms for disease and local conceptions of disease causation, in order to be able to explain well how HIV is transmitted and treated. In societies where wasting illnesses are thought to be due to witchcraft or spiritual transgression, being able to explain about HIV in that context is necessary, being sensitive to the individual's beliefs. The counsellor should have adequate knowledge of the transmission, infection and disease. For example, he/she should know the modes of transmission and how to avoid infection, the

window period during which time an antibody test may be negative, the latent period, the symptoms of the disease and the prognosis and should know what is available locally in terms of support and treatment. Counsellors should not attempt to impose their own attitudes and religious beliefs.

An assessment should be made of the individual's ability to deal with a positive result, and the risk of depression, self-harm or suicide. Whether the person wishes a relative or close friend to share the results with them should be explored, and if he or she seems unlikely to be able to cope with a positive result, or to have inadequate social support, then this should be taken into account when discussing whether the person should undergo testing. The counsellor should be aware of the possible social effects that a positive test results may have in the community and take measures to prevent inadvertent disclosure or breaches of confidentiality. It may be appropriate to counsel and test a married or cohabiting couple together, but the counsellor should understand that there might be subsequent social problems, particularly if there is discordance between the results of the two individuals. In some societies, an HIV positive woman may be divorced or be subject to violence.

A checklist for post-test counselling is presented in Box. 2.

Box 2. Post-test counselling[7]

Greetings
Warming up, making the individual feel comfortable
Brief review of what happened in previous session
Actively include significant other person
Check if individual still wants to know test results
Reveal the results*
Observe the reaction and provide support
Allow time for expression of feelings
Assess psychological state
Assess level of understanding and upgrade knowledge if necessary
Identify problems
Identify solutions/resources
Draw up plan of action
Information on HIV prevention
Guidelines on living longer
Summarize
Date of next appointment (follow-up)
**Checklist for revealing HIV test results*
Keep the message clear and simple
Ask yourself what the result means to the patient
Wait for questions
Do not argue with denial
Do not destroy all hope
Do not say anything that is not true

COUNSELLING CHILDREN

Counselling in the case of HIV testing a child is a difficult issue. In young children, the parent or guardian will need to be counselled, and the counsellor should be aware of the implications

that a positive result in a young child will have for the mother's HIV status, as mother-to-child-transmission is the most likely route of infection. In older children who may have been sexually active (with or without consent) an assessment should be made as to whether it is culturally and individually appropriate to counsel the child with or without the parent or guardian.

COUNSELLING WITHOUT TESTING

It may not always be possible or necessary to offer HIV testing when counselling is required. This situation might arise when there is a reasonable certainty of the diagnosis, for example when an individual has clinical features of AIDS. Even without access to testing, counselling may cover many of the same issues, review individual knowledge, conduct a risk assessment and review the level of understanding. The possibility of an HIV related diagnosis should be discussed, given the individual's level of risk and symptoms. Personal risk reduction and the implications of infection may still be covered. The individual may require referral to clinical services for further care and support. It is also appropriate to offer counselling when HIV testing is available, but for some particular reason the individual does not wish to undergo testing, perhaps because of fear or concerns over confidentiality.

ETHICAL ISSUES IN HIV TESTING AND COUNSELLING

Individuals should not be tested for HIV without their informed consent

'Informed' means not only that they understand that a test for HIV is being conducted, but also that they are educated about HIV and its modes of transmission, and understand the benefits or risks to them of knowing the result and what they can expect from local medical, social and community services should they have a positive result. Confidentiality is a key to the confidence of those being tested. They must feel they can trust the counsellor involved and also that their sample will be handled in a confidential manner. This may require coding of the sample details so that staff handling the transport and processing of the sample and result cannot easily identify the individual. Care must be taken to ensure that there is no opportunity for results to be assigned to the wrong person. People may also be concerned that their test result may be communicated to employers, police, relatives and so on and they must be confident that this will not occur.

HIV-TESTING IN LEPROSY

HIV/AIDS causes a wide variety of dermatological and neurological symptoms and signs, and therefore HIV testing may be appropriate as part of the diagnostic work-up in some patients suspected of having leprosy in areas of high HIV prevalence. Whether HIV infection is a risk factor for leprosy has been investigated in several populations, and with a few exceptions[8] the answer has been no. Some studies have indicated that HIV may predispose to reactions or relapse.[9–12] The cumulative evidence indicates that HIV is not an important determinant of leprosy, perhaps because HIV-infected individuals in leprosy endemic areas succumb to the classical AIDS-related conditions before the leprosy bacillus is able to take advantage of the immunosuppressed state to infect the individual or cause disease. HIV testing in leprosy patients is reliable. Reports that there may be false positive HIV results in

leprosy patients due to cross-reactive antigens have not been borne out by detailed investigations.[13]

All of the issues involved in counselling and testing for HIV apply to patients with leprosy, with the added concern that the occurrence of leprosy and HIV in a single individual may increase the problem of social stigmatization.

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SCIENCE COMMENTARY

Modern genetics and leprosy susceptibility

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With the advent of the genome projects, both human and pathogen, our whole approach to studying the role of host/pathogen interactions in determining infectious disease susceptibility has undergone a remarkable transformation.

The first impact that modern genomics had on analysing genetic susceptibility to infection was the ability to use physical mapping data and 'big DNA' (yeast and bacterial artificial chromosomes, cosmids) clone contigs to pinpoint a gene and identify it on the basis of its genetic map location. The first elegant example of this was the positional cloning[1] of the murine natural resistance associated macrophage protein 1 (*Nramp1*) gene, variously known in earlier studies as *Ity*, *Lsh* and *Bcg* for its role in controlling innate resistance and susceptibility to *Salmonella typhimurium*, *Leishmania donovani* or *Mycobacterium bovis* BCG infection, respectively. In this case, ability to clone the gene on the basis of its map location was vitally dependent on the ability to 'genotype' individual mice according to their phenotypic response to infection. For all three infections (e.g. reference[2]), segregation of disease phenotypes in the F2 and backcross progeny made between resistant and susceptible inbred mouse strains followed perfect Mendelian inheritance, with resistance almost completely dominant and individual mice falling clearly into non-overlapping resistant or susceptible phenotypes on the basis of liver or spleen pathogen counts. The identification of *Ity/Lsh/Bcg* gene was highly relevant to human disease susceptibility, since we had all been anxious to know whether a human homologue would also control susceptibility to leprosy and/or tuberculosis. In humans, NRAMP1 is globally linked or associated with tuberculosis[3–8] and is also linked to leprosy susceptibility[9] and ability to mount a Mitsuda type skin test reaction to leprosy antigens[10] in Vietnam. These studies provided strong support for the concept that murine models of disease can identify disease susceptibility genes that will be important in humans.

The Vidal study[1] was a model of perfection for its time. It involved extensive studies using exon trapping and analysis of tissue expression profiles of candidate exons/genes within the narrowed down interval known to contain the gene in order finally to identify the macrophage-expressed Nramp1 protein, now renamed solute carrier family 11a member 1 (Slc11a1) on the basis of its function as a divalent cation/proton antiporter.[11] Now that the first draft of the human sequence is published,[12,13] we should be able directly to identify the chromosome linked to susceptibility to infection in humans and simply inspect the

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region under the linkage curve to identify the disease-associated gene. Or is it really that simple?

The first example of direct identification of a human infectious disease susceptibility gene using modern genomics was another very elegant study in which egg output for schistosomiasis was measured in large multicase pedigrees in Brazil and shown to segregate as a Mendelian single gene trait.[14] DNAs from a subset of 11 informative complex multicase pedigrees was used in a 10–15 centimorgan (cM) microsatellite genome scan, i.e. the DNA for 142 individuals in these pedigrees were genotyped for ~300 microsatellite markers across the genome, and multipoint linkage analyses performed to locate the single major gene that had been predicted. Luckily, only a single major linkage peak was identified with a peak parametric lod score (log likelihood for linkage) of 4·74 (i.e. >10,000:1 odds in favour of linkage). However, although the peak lod score was found near the locus containing the gene (CSF1R) encoding the receptor for colony stimulating factor 1, the linked region contained a host of other potential candidate genes including those encoding interleukin (IL) 4, IL5, IL9, IL13, and interferon regulatory factor 1 (IRF1), for all of which a plausible case could be built for their involvement in determining susceptibility to schistosome infection. Unfortunately, the ability to fine map the region and pinpoint the real susceptibility gene relies on much larger samples sizes and linkage disequilibrium mapping, and such studies are even now still in progress.

The second published attempt at mapping infectious disease susceptibility genes via a genome scan was for tuberculosis, this time using non-parametric linkage analysis of affected sibling pairs.[15] Initially, 92 affected sibling pairs plus parents collected from The Gambia and South Africa were genotyped for 299 microsatellite markers. Seven regions of the genome showed maximum lod scores (MLS) >1 ($P = 0{\cdot}05$). Twenty-two markers from these regions were typed in a second set of 82 affected sibling pairs plus parents, with only chromosomes 15q (MLS = 2) and Xq (MLS = 1·77) retaining lod scores suggestive of linkage but this time at odds ≤100:1. This does not achieve the levels of significance recommended for a genome-wide scan,[16] probably reflecting the fact that this sample size is not sufficient to detect linkage for genes contributing to the complex disease phenotype of pulmonary tuberculosis. It is likely that the search for susceptibility genes for tuberculosis will require much larger sample sizes, and much more effort, to identify the multiple genes that are likely to be contributing to overall disease susceptibility.

The third published example of genome scanning to identify susceptibility genes for infectious disease is the recently reported study on leprosy.[17] In this case, the authors were more successful in ultimately identifying a region on chromosome 10p13 with a non-parametric MLS of 4.09 ($P = 0{\cdot}000007$) (Figure 1). To obtain this, 388 markers were initially typed on 103 affected sibling pairs plus parents. Twenty-eight regions were identified with MLS >1·0. Thirty-seven markers from these regions were typed in an additional 142 affected sibling pair families. In the overall analysis, only chromosome 10p13 showed a multipoint MLS >3·0. A further eight markers typed in this region yielded the final MLS of 4·09. Examination of public domain databases provides a single obvious candidate, the gene encoding mannose receptor C type 1 (MRC1), that maps under the 10p13 interval[18] positive for linkage to leprosy susceptibility. Recent studies[19] provide new structural insights into the molecular deciphering of mycobacterial lipoglycan binding to C-type lectins such as the macrophage mannose receptor, providing a rational basis to target MRC1 as the most appropriate candidate within the linkage interval on 10p13. Polymorphisms within the MRC1 gene are now being analysed in allelic association studies.

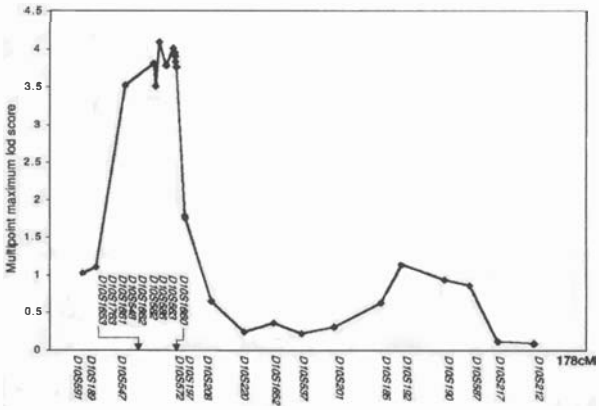

Figure 1. Maximum likelihood multipoint map for 25 microsatellite markers on chromosome 10, including 8 markers flanking *D10S548*. The maximum multipoint MLS for the region is 4·09 (P value = 0·000007) and corresponded to *D10S166*. Reproduced with permission from Siddiqui *et al.*[17]

The results of this Indian study are interesting in relation to previous studies suggesting a role for HLA in determining leprosy susceptibility, including many studies based in India. In the genome scan, markers within HLA were not positive for linkage. Hence, the authors conclude that HLA is not a major susceptibility gene in India.[17] In our own studies of leprosy in Brazil, we have found a peak parametric lod score for linkage to HLA of 5·78 ($P = 0{\cdot}00000025$) in 73 two and three generation extended multicase pedigrees analysed using combined segregation and linkage analysis,[20] similar to that used in the schistosomiasis study. Affected sib pair analysis of the same families for 63 nuclear families with 138 affected sibling pairs (equivalent to 91 affected sib pairs plus parents after weighting for multiple affected sib pairs in a family) provides an MLS of only 2·12 ($P = 0{\cdot}002$), demonstrating the increased power provided by the larger two and three generation pedigrees. Nevertheless, the locus-specific risk for siblings of patients (λ_s) for the peak of linkage at HLA (calculated from the ratio of the expected proportion of affected sibling pairs sharing zero alleles identical by descent (0·25) and the observed proportion[21]) based on this set of affected sibling pairs is 1·79, compared to a value of 1·66 for the peak of linkage on chromosome 10p13 in the Indian study (245 independent affected sibling pairs[17]). Hence, we may conclude that HLA makes an equivalent if not greater contribution to the total genetic component of susceptibility to leprosy *per se* in Brazil as the chromosome 10p13 gene does in India, highlighting the fact that different genes may contribute to disease susceptibility in different geographic regions. Alternatively, or in addition, the Indian study took place in an area where the incidence of paucibacillary leprosy was high and none of the families had only multibacillary affected siblings, whereas the Brazilian study took place in an area with high incidence of multibacillary leprosy. Interestingly, detailed investigation of HLA in a similar sample of 98 multicase pedigrees with pulmonary tuberculosis from the same region of Brazil failed to show any evidence for linkage or allelic association (I. Davidson, J. M. Blackwell & M.-A. Shaw, unpublished observation). For leprosy, allelic association was highly significant in both the HLA DR/DQ ($P = 0{\cdot}001$–$0{\cdot}024$) and TNFA ($P = 3{\cdot}6 \times 10^{-5}$) gene regions.[20] Hence, these two important mycobacterial infections of humans show quite distinct genetic regulation, particularly with respect to the role of the major histocompatibility complex in this region of Brazil.

So what can we learn from these new genome-based family studies of susceptibility to infectious disease? Firstly, two of the three studies performed to date have identified major genes controlling disease susceptibility that conform to the genome-wide criteria for statistically significant linkage.[16] In both cases, obvious candidate genes have been identified under the region of linkage. For schistosomiasis, a candidate rich region was identified, which has made it difficult to identify the specific gene regulating egg output. For leprosy, there appears at present to be just one obvious candidate (MRC1) under the linked region in India, but confirmation of its role has yet to be published and its global relevance to leprosy susceptibility requires further investigation. For tuberculosis, genetic regulation appears more complex, and will require further work to uncover the multiple genes and mechanisms likely to regulate susceptibility. As for schistosomiasis, this might involve careful stratification of the disease phenotype, with better recording of clinical criteria across the spectrum of disease. The same is true for leprosy, where the studies in both India and Brazil have focussed on areas differing in incidence of paucibacillary versus multibacillary leprosy. Nevertheless, these ground-breaking studies applying modern whole-genome approaches to infectious disease susceptibility promise to yield rich rewards in furthering our understanding of the genes and mechanisms that regulate infectious disease susceptibility.

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CASE REPORT

Borderline tuberculoid leprosy of the scalp

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Summary A case of borderline tuberculoid leprosy involving the hairy scalp is reported. To the best of our knowledge, only two paucibacillary leprosy patients with scalp lesion have been reported, and in only one was the scalp covered with hair.

Introduction

Involvement of the scalp in leprosy is considered to be rare, and few cases with scalp lesions of leprosy have been reported.[1–6] In most of these cases, the patients had multibacillary leprosy. We report a case of borderline tuberculoid leprosy on the hairy scalp.

Case report

A 30-year-old male presented an erythematous lesion with tingling sensation on the face and scalp of $1\frac{1}{2}$ years duration. On examination, he had a well defined, warm, non-tender, erythematous swollen plaque of about 10×15 cm on the butterfly area of the face and the whole of frontal and parietal area of the scalp (Figure 1). Eyebrows and scalp hairs were intact. Touch and pain sensations were impaired on the lesion and temperature sensation was absent. There was no nerve thickening or tenderness. Weakness of the orbicularis occuli and frontalis muscles was observed. A clinical diagnosis of borderline tuberculoid (BT) leprosy in type I reaction with lagophthalmus was made.

Skin smears from the routine and selective sites were negative for AFB. A biopsy from the skin lesion on the scalp showed discrete and confluent granulomas composed of epitheloid cells, lymphocytes, histiocytes, few Langerhans and foreign body type giant cells around blood vessels and skin adenexa. The dermis showed dilated lymphatic channels and blood vessels. The granulomas were seen replacing the base of hair follicles. The dermal nerves were inflamed. The granuloma fraction was 60%. Acid fast stained sections showed few scattered bacilli within the nerves and in smooth muscles. They were predominantly granular and beaded.

The patient was started on the WHO paucibacillary regimen along with 40 mg prednisolone in tablet form for type I reaction and weakness of the facial nerves. The dose of

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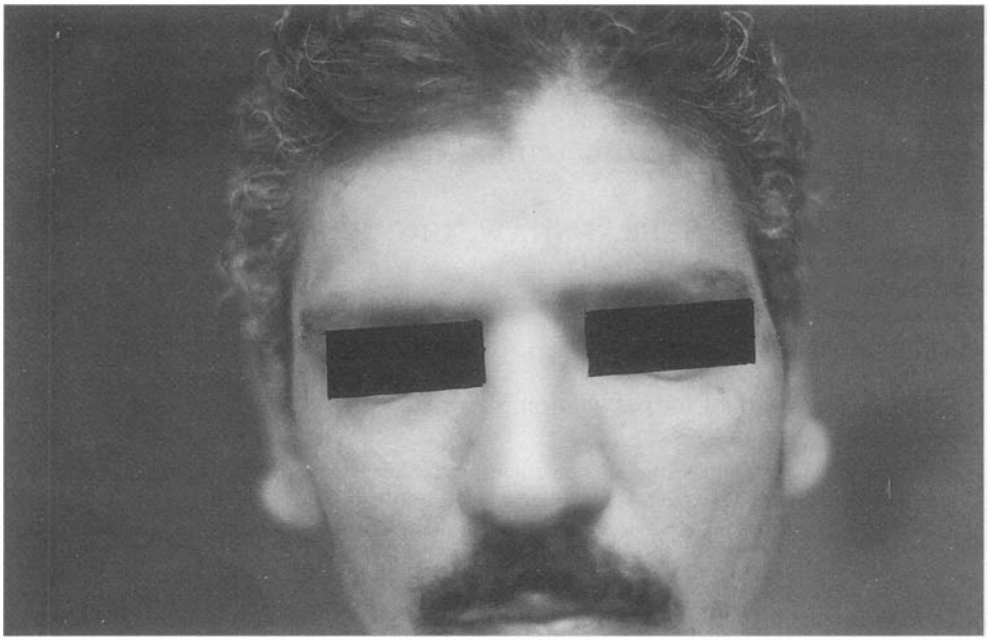

Figure 1. Clinical photograph showing the borderline tuberculoid lesion on the face extending to the hairy scalp.

prednisolone was gradually tapered according to the response, and it was stopped after 6 months. The patient was also recommended regular exercise for lagophthalmus.

Discussion

The scalp is considered to be an immune zone in leprosy. Anish demonstrated a higher temperature of the hairy scalp as compared to that of the forearm.[7] As *Mycobacterium leprae* has a predilection for cooler parts of the body,[8,9] the scalp is usually spared.

In most of the cases reported with scalp lesions the patients had either lepromatous or borderline lepromatous leprosy[1–4] and in many of these cases the patients were bald.[3] To the best of our knowledge, only one case each of tuberculoid and borderline tuberculoid with leprosy lesions on the scalp have been reported so far.[5,6] While the tuberculoid plaque was present on the hairy occipital area of the scalp,[9] the borderline tuberculoid lesion was seen on the scalp of an Indian who had performed the ritual of shaving of the scalp hair throughout his life.[8] In our patient, the leprosy lesion involved the whole of the frontal and the parietal area of the scalp. Hair on the lesion remained intact in spite of the lesion having been present for $1\frac{1}{2}$ years (Figure 1). Though rare, the hairy scalp can be involved in borderline tuberculoid leprosy, and the hair growth may appear normal.

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CASE REPORT

The Lucio-Alvarado-Latapi form of leprosy

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Introduction

Lucio's leprosy is characterized clinically by diffuse, generalized, erythematous infiltration with no nodules. Other clinical manifestations are rhinitis, alopecia, telangiectasia of face and chest, facial acne rosacea and livedo on the lower limbs.[1–3] Skin smears for acid-fast bacilli are positive from any site, since bacterial infection is diffuse. The histopathology shows characteristic features of diffuse granuloma Virchow cell infiltration and new vascular formation.[1,2]

This variety of leprosy may be accompanied by Lucio's phenomenon characterized by multiple and acute necrotizing lesions.[4–7]

Treatment with multi-drug therapy (rifampicin, dapsone and clofazimine) has proved satisfactory with clinical improvement.[1–3] Corticosteroids are prescribed when Lucio's phenomenon is present.[6–8]

Case report

A 52-year-old white man from Crato-Ceará-Brazil presented to the outpatient dermatology clinic at Walter Cantideo University Hospital with erythematous skin lesions. He had a history of syphilis treated with penicillin 16 years earlier and focal glomerulosclerosis with nephrotic syndrome for 8 years. He was taking prednisone (0·25–1·0 mg/kg/day), frusemide and ranitidine. Examination revealed diffusely erythematous and infiltrated skin; telangiectasia on face and chest; alopecia of chest; violet-erythematous livedo on lower limbs and coalescent yellow maculae of irregular surface on his enlarged nose. There was no nerve involvement.

Investigation showed: acid fast bacilli on three skin smears (chest wall, neck and thighs) and smears from ear lobe and elbow: bacteriological and morphological indexes were not

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performed because at the time of diagnosis, Brazil's Health Ministry did not require them for diagnosis. Other tests included erythrocyte sedimentation rate (75 mm), fluorescent treponemal antibody [absorbed test (FTA-ABS) (-ve)], Veneral Disease Research Laboratory test (VDRL) (1:2), antinuclear antibody (-ve), Mitsuda (-ve), Medina (-ve), cryoglobulin (-ve), haemoglobin at the time of presentation (14·8 mg/dl), white cell count range at the time of presentation (9500/mm^3), serum creatinine (1·1 mg/dl) and serum glucose (80 mg/dl). Alanine and aspartate aminotransferases, complement, search for parasites in faeces and protein electrophoresis showed no abnormalities.

Skin biopsy from the nose revealed inflammatory infiltration with numerous bacilli and significant hyperplasia of sebaceous glands. Renal biopsy showed focal glomerulosclerosis. Three skin biopsies from chest, neck and thighs demonstrated the papillary layer of the dermis as a clear band. Deeper in the dermis, there was diffuse inflammatory infiltration with 'foamy' macrophages with no nodule formation. Vascular proliferation was visible under H&E staining and numerous bacilli forming globi were observed with Wade-Fite staining.

Multidrug therapy treatment was started and by 3 months there was remission of erythema with wrinkling of the skin. Skin smears showed fragmented bacilli and a skin biopsy from the chest wall showed resolution of the inflammatory infiltration with numerous bacilli. After 2 years of multidrug therapy, the infiltration of skin had regressed and there was diffuse hyperpigmentation due to clofazimine. Skin smears were negative. The nephropathy was well controlled with prednisone (0·25–1 mg/kg/day).

Discussion

The diagnosis of Lucio's leprosy is difficult because in many cases the patient has no clear signs of leprosy. In this case, other factors contributed to the diagnostic difficulty. Firstly, the association with rinophyma and telangiectasia obscured the clinical perception of leprosy. Secondly, the use of glucocorticoids to control renal disease probably altered the progression of leprosy, possibly inhibiting a Lucio's phenomenon. Thirdly, there was the probable wrong diagnosis of syphilis and treatment with penicillin 16 years ago; the patient had a positive Veneral Disease Research Laboratory test but negative fluorescent treponemal antibody-absorbed test, which is more specific. The patient probably already had Lucio's leprosy at that time with a false positive VDRL test. There has been evidence that a false-positive VDRL with intense reactions occurs constantly in Lucio's leprosy.[1,3] A study carried out in Mexico demonstrated 16% of false-positive VDRL in the sera of 25 patients with diffuse lepromatous leprosy.[7]

The diagnosis of this case was based on clinical and microscopic features. Clinically, there was diffuse erythematous infiltrated skin, with telangiectasia, livedo on lower extremities, alopecia in some areas of the skin and a long evolution without the appearance of definite nodules or plaques. On microscopic examination, diffuse granulomatous, Virchow cell infiltration and new vessel formation were observed.

The occurrence of Lucio's leprosy in countries other than Mexico and Costa Rica is rarely described, although there have been reports of cases in California, Louisiana, Hawaii and Minas Gerais-Brazil.[1,2,5] It is interesting that this case was diagnosed in a patient from the city of Crato-Ceará-Brazil, which has a very high prevalence of leprosy. Thus it is possible that more cases of this form of leprosy are yet to be diagnosed.

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Obituary

PROFESSOR LE KINH DUE (1925–2001)

Professor Le Kinh Due, an eminent leprologist and dermatologist, former Director of the National Institute of Dermato-Venereology (NIDV), Hanoi, Vietnam, died on 6 February 2001.

Professor Le Kinh Due was born in Ha Tinh province on 10 May 1925. He had his early education in Hue City and took his medical degree at Hanoi Medical College in 1952. Subsequently, he served the cause of National Independence in the capacity of surgeon. After 1954, he received specialized training in immunology and histopathology of the skin at Humbold University, Berlin.

In 1975, Professor Le was appointed to the Chair of Dermatology, Bach Mai Hospital, and became Head of the Dermato-Venereological Department of Hanoi Medical College, where he enjoyed a long and distinguished teaching career. He took up the position of Director of NIDV and President of the Vietnam Dermatology Association in 1982.

Professor Le began his career in the field of leprosy control over 40 years ago, in the capacity of director of his country's leprosy programme. Over the years, he made a major contribution to establishing a nationwide anti-leprosy network, from central to grassroots level. In 1981, a national leprosy elimination programme was launched by Professor Le and his colleagues under the guidance of the Ministry of Health; it was successfully implemented in a stepwise manner, and proved very fruitful. In recent years, the stigma attached to leprosy has virtually been eliminated, even in remote areas.

Professor Le was the author of many books on leprosy, skin diseases and sexually transmitted diseases. He visited and worked in many countries as a WHO consultant on leprosy, and was awarded a 'Health for All' medal and the Sasakawa Health Prize by the WHO in 1988 and 1995, respectively. He also received many prestigious awards for his work from the Government of Vietnam.

Professor Le is survived by his wife and two sons. He will be greatly missed by his co-workers, students and colleagues.

(Condensed from a longer article written by Dr Tran Hau Khang, Vice-Director, NIDV)

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International training in 2002
January 21–February 22
Prevention and management of disabilities

Target group: physiotherapists, occupational therapists, podiatrists as well as experienced leprosy workers involved in POD. Emphasis on both patient care (early detection of nerve function deterioration, health promotion, problem solving) and programme management (POD management, home-based care and rehabilitation).

March 11–March 29
Clinical leprosy and tropical dermatology for physicians

Highly recommended for the participants in the following 'Management of combined programmes' course who need to refresh their knowledge of clinical leprosy and tropical dermatology. The course can also be taken on its own by physicians responsible for diagnosis, treatment and care of patients with leprosy in either a hospital or a control programme setting.

April 1–April 19
Management of combined leprosy and tuberculosis control programmes for physicians

Target group: experienced physicians responsible for managing a leprosy and TB control programme at the regional level or above. Emphasis on programme management: needs

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analysis, action plan, implementation of activities, supervision, evaluation, management of POD. Participants without leprosy experience should also take the preceding 'Clinical leprosy' course.

May 6–May 24
Essentials of leprosy and tuberculosis for administrative and programme support staff

Target group: administrative and managerial staff without a medical background, working in leprosy and TB programmes and donor agencies. Objectives: to gain a better understanding of the two diseases, to communicate more effectively with the medical staff and to contribute more efficiently in decision making and priority setting.

September 9–September 27
Essentials of leprosy for physicians

This course is for participants new to the field of leprosy or who need to refresh their knowledge. It aims at physicians responsible for diagnosis, treatment and care of patients with leprosy in either a hospital or a control programme setting.

September 30–October 11
Clinical leprosy for senior field staff

Highly recommended for the participants in the following 'Management of combined programmes' course who need to refresh their knowledge of clinical leprosy. The course can also be taken on its own.

October 14–November 1
Management of combined leprosy and tuberculosis control programmes for senior field staff

Target group: experienced nurses, paramedical workers or supervisors responsible for leprosy and TB control at the district (or equivalent) level. Emphasis on planning, implementation, supervision and evaluation of control activities, with special attention to POD, health promotion and support functions. Participants without leprosy experience should also take the preceding 'Clinical leprosy' course.

November 4–November 22
Tuberculosis Programme Managers Course

This course is organized jointly with the Nuffield Institute for Health, Leeds University, UK. Target group: health managers responsible for TB control activities at the national or

intermediate level. Course objectives: to present the concepts on which TB control strategies are based and to identify key program elements. The course modules are organized around the stages of the programme management cycle.

November 25–December 6
Training of trainers course

This course is recommended for all cadres of health workers (physicians, senior field staff, physiotherapists, programme managers, nurses, etc.) who help health workers to learn. The course covers task analysis, setting up educational objectives, preparation of lesson plans and teaching methodology, including bedside teaching, assessment techniques, designing appropriate audio-visual aids and teaching programme evaluation.

In-service training

ALERT can offer in service training in physiotherapy, surgery, dermatology, ophthalmology, etc. Students will have the opportunity to practice in the 240 bed hospital and in the field and use self-study facilities such as CD-ROMs, video, slide programmes and library. It is possible for trainees attending courses to opt to stay on for in-service training after the courses have finished. The duration and content of the in-service training period will be arranged according to the experience and the interest of the individual trainee.

Training fees

Students stay at the ALERT hostel. Each student has a single study room. The bathroom is shared between 4 students.

Basic training fees amount to US$ 460 per week. This covers tuition, full board and lodging, laundry facilities, airport service, weekend transportation and Ethiopian Birr 30 per day pocket money. Field trips are an additional US$ 25 per day for transportation, facilitation and living expenses. Special rates are available for long-term in-service trainees. Please note that ALERT does not provide any sponsorship.

Health

ALERT does not provide health insurance. Please make sure that you are suitably insured before coming to Ethiopia.

You need a valid yellow fever vaccination certificate. Malaria prophylaxis is recommended. Although there is no malaria at ALERT, you may be exposed during field visits.

ALERT is situated at 2,400 meters above sea level so the climate can be cold. It is recommended that you bring warm clothes and rain wear.

Visa formalities

As soon as you are accepted for a course, we will send you a letter of acceptance which you may use to obtain a visa for Ethiopia. Because administrative formalities can be time consuming, we advise you to apply as early as possible.

If your country has no Ethiopian Embassy, please send your passport number, nationality and your name as written in the passport to ALERT at least three weeks before you are due to leave. We will then fax your entry permit number. You need this to get on the plane. At Addis Ababa airport immigration, you will be issued with an entry visa which you will have to pay personally in hard currency. You should bring US$ 25 for this.

Upon departure, you need US$ 20 to pay for your airport tax.

If you are interested in any of these training opportunities, contact the Training Division of ALERT. You will be sent a brochure with practical information about staying at ALERT and an application form which you should fill and send at least 3 months before the course starts.

If you would like more information about a specific course, you can visit our web site www.telecom.net.et/~tdalert or you can request a detailed course schedule form the Training Division of ALERT

ILEP Catalogue of Training Courses for Leprosy 2001

This A5 booklet of 32 pages is available from The International Federation of Anti-Leprosy Associations, 234 Blythe Road, London W14 0HJ, England (Fax +44 (0)20 7371 1621. E-mail: ilep@ilep.org.uk). The Introduction reads as follows:

> The ILEP Catalogue of Training Courses brings together information on international courses and in-service training available to health workers. Training courses on leprosy, tuberculosis, dermatology, health management and community based rehabilitation are included. This reflects the diversity of the work supported by ILEP members.
>
> We would like the information provided to be as comprehensive as possible and for this we rely on information and feedback from ILEP Members, Training Centres, Course Organisers and Participants. We thank all those who have contributed towards this latest edition.
>
> If you would like information on your training centre and the courses you run to be included in this catalogue please use the form at the end of the present catalogue (page 29). We also welcome any suggestions on how this catalogue can be made more useful.
>
> Inclusion of a training course in this catalogue does not signify its endorsement by ILEP. Also please note that ILEP is not a funding agency and cannot consider sponsoring trainees. For further information please contact the Training Centres directly or ILEP.

Where appropriate, there is a translation in French. The countries covered include Ethiopia, Mali, South Africa, Uganda, India, Nepal, Spain, Brazil, Mexico and USA. Pages 25 and 26 describe courses on tuberculosis run by the International Union Against Tuberculosis and Lung Disease, 68 Boulevard Saint-Michel, 75006 Paris, France (Fax +331 43 29 90

87. E-mail: union@iuatld.org). Page 27 lists other international tuberculosis courses as follows:

- Management of National Tuberculosis Programmes (AMRO). Peru (annual) in Spanish.
- International Tuberculosis Courses—WHO/EURO—Warsaw, Poland.
- International Tuberculosis Course on Tuberculosis Control—WHO/SEARO—Kathmandu, Nepal. Held annually in April.
- International Tuberculosis Course—AMRO. Cuba and Chile (annual). Spanish.
- International Course on Epidemiology and Tuberculosis—IUATLD and AMRO. Held annually in Nicaragua in Spanish.
- Laboratory Course for National Tuberculosis Programmes—WHO/WPRO. To train laboratory managers for NTPs.
- International Tuberculosis Course for National Tuberculosis Programmes—WHO/WPRO—Beijing.
- International Epidemiology and Tuberculosis Control Course—Managua, Nicaragua. Sponsored by the Ministry of Health of Nicaragua, PAHO/WHO and the IUATLD. Spanish. For further details please contact IUATLD (see previous page).
- International Course on '*New Paradigms in the Management of National TB Control Programmes*' in Peru. Ministry of Health, Peru and PAHO/WHO. Spanish. For professionals at the national and intermediate levels who work in National Tuberculosis Control Programmes. Contact Dr P. G. Suarez, Director of the National Tuberculosis Control Programme, The Ministry of Health, Av. Salaberry cuadra 8 Lima 11, Peru, Tel: 424 3571.
- International Epidemiology and Tuberculosis Control Course, Chile. Sponsored by the Ministry of Health and other organisations. Spanish. For more information contact Dr M. Zuniga, Director of the National Tuberculosis Control Programme in the Ministry of Health, Fax: 562 630 0467.
- Laboratory Training courses are held on an ad-hoc basis. Please contact Dr Adalbert Laszio of the LCDC in Canada via e-mail: alaszlo@hpl.hwc.ca.

Contact: Carolyn Mohan, PAHO, 525 Twenty-third Street, NW, Washington DC, USA
Tel: 001 202 974 3713
Fax: 001 202 974 3656
E-mail: mohancar@paho.org

Finally, page 28 lists courses run by The Royal Tropical Institute (KIT) in Amsterdam:

Courses: Organized by the Royal Tropical Institute

- International Course in Health Development (ICHD).
- International Course on District Health Care at locations in Amsterdam, Mali (together with ENMP), Zambia (together with PAID—ESA), Vietnam (together with HSPH).
- Training Workshops on Women, Gender and Development.
- Training Workshops for Trainers on Women, Gender and Development.
- Training Workshops on Gender, Citizenship and Good Governance.

Modular Training Courses in the following fields:

- Managing Programmes for Leprosy Control.
- Health Policy and Management, Health Systems Research.

- Health Financing, Health Management Information Systems.
- IEC, Human Resources Development for Health.
- Reproductive Health, Nutrition.
- Communication and Teamwork.
- Emergency Aid and Disaster Preparedness.
- Biomedical sciences.
- EPI-info.
- Quality Assurance in Health Systems.
- Health Promotion.

Contact: Ms Jenny Postema. Institution: Royal Tropical Institute (KIT), P.O. Box 95001, 1090 HA Amsterdam, The Netherlands.

Tel: +31 20 568 8256/8239
Fax: +31 20 568 8677
Website: http://www.kit.nl

16th International Leprosy Congress

The 16th International Leprosy Congress will be held from August 4th to 9th, 2002, at the Convention Center, Salvador, Bahia, Brazil. The languages of the Congress will be English and Portuguese. Posters illustrating participants' work and research will be on exhibit throughout the Congress. In addition, paid exhibit space can be reserved for products or organizations.

Presentations at the Congress will cover all aspects of leprosy and its control, including experimental and laboratory science, clinical science, program planning and management, training, education and social aspects. Each day, a State-of-the-Art lecture will be presented on a key issue.

To receive information regarding fees and registration, please contact the Secretary for Administration, Instituto Lauro de Souza Lima, Rodovia Comandante Joao Ribeiro de Barros, Km 225/226, Caixa Postal 3021, CEP 17001-970, Bauru, SP, Brazil. Fax +55 (14) 221-5914, e-mail: brazil_leprosy@ilsl.br.

20th World Congress of Dermatology

The next World Congress of Dermatology will be held in Paris from 1st to 5th July 2002, at the Palais des Congrès. For further information, please contact the Congress Secretariat: P. Fournier, Colloquium, 12 rue de la Croix St Faubin, 75011 Paris, France. Tel: +33-1-44641515, Fax: +33-1-44641516, e-mail: p.Fournier@colloquium.fr, website: www.derm-wcd-2002.com.

SER Guidelines in French

The French translation of Guidelines for the Social and Economic Rehabilitation of People Affected by Leprosy 'Directives pour la réadaptation sociale et économique des personnes

atteintes de la lèpre' is now available. Based on combined experience from ILEP programmes, this book is aimed both at people working in social and economic rehabilitation and programme managers thinking of becoming involved in this area.

Please use the attached form to order your copies now.

ILEP Order Form

Guidelines for the Social and Economic Rehabilitation of People Affected by Leprosy

Principal Author: Peter Nicholls
Translated by: Dr Alexandre Tiendrebeogo
Prepared on behalf of the ILEP Medico-Social Commission, 1999
ISBN: 0 9475 4318 X

French Edition

To place your order, complete the form below.

Organization:	**Quantity required:**

Address to which order to be sent:

E-mail:

Please indicate here if airmail postage is required for orders to field projects, as this will be charged to the ILEP Member ☐

Please return your orders to: Lindsay Ramsbottom, ILEP, 234 Blythe Road, London W14 0HJ, UK.
Fax: +44 (0)20 7371 1621, e-mail: lramsbottom@ilep.org.uk

Publications on leprosy in Spanish

We are grateful for copies of *Revista de Leprologia Fontilles* from the Sanatorio San Francisco de Borja. 03791, Fontilles, Alicante, Spain. Apart from articles on leprosy from many parts of the world, this journal regularly carries information about training courses (in Spanish) held at the sanatorium, together with detailed information on recent publications in the world literature.

The Revista Internacional de Dermatologia y Dermocosmetica Clinica publishes selected articles from the *International Journal of Dermatology* (Official publication of the

International Society of Dermatology). It is sponsored by Saned (Sanidad ediciones) and edited from Madrid: manuscripts should be sent to Saned, SL, JJ Vilata Corell, Capitán Haya 60, 28020, Madrid, Spain. Each issue deals mainly with dermatological subjects, but also has a section on leprosy.

Robert Cochrane Fund for Leprosy, UK

The Fund, in memory of the great leprologist Robert Cochrane, is administered by the Royal Society of Tropical Medicine and Hygiene. It is to be used to finance up to three travel Fellowships each year, to a maximum value of £1000 each. The Fund will support travel for:

Leprosy workers who need to obtain practical training in field work or in research
Experienced leprologists to provide practical training in a developing country

There is no restriction on the country of origin or destination providing the above requirements are fulfilled.

Application forms are available from the Society and completed forms must be received by the Society at least 6 months ahead of the proposed visit. All applications must be sponsored by a suitable representative of the applicant's employer or study centre, and agreed by the host organization. A two-page report on the travel/study should be submitted to the Society within 1 month of the recipient's return.

Apply: Robert Cochrane Fund for Leprosy, Manson House, 26 Portland Place, London W1N 4EY, UK. Fax: +44 (0)171 436 1389.

The Malaria Red Trunk

Under the general heading of improving malaria information support for health professionals in Southern Africa, a 'Malaria Red Reference Initiative' was developed in August 1999 between WHO and the University of Zimbabwe Medical Library. The essential components consist of 1) a Southern Africa Malaria Red Information centre, 2) The Malaria Red Trunk, 3) The Malaria Red File and 4) E-mail and Electronic Sources of Information. Further information on these is obtainable from Dr Graham Root, Research, Monitoring and Evaluation Officer, Southern Africa Malaria Control Programme, WHO, 95 Park Lane, Harare, Zimbabwe. Fax (263) 04 728998. E-mail: groot@samara.co.zw

By way of a progress note, Dr Root has recently written to us indicating that the Red Trunk has been distributed to 10 countries in Southern Africa. Trunks are given to each National Malaria Control Programme, the WHO country office, a few provinces and several research institutions. The response so far has been very positive and it is now intended to take the trunks to the district level. The contents will be reduced, concentrating on core texts on malaria.

[Following the success of the Blue Trunks from WHO, there may now be room for discussion on the provision of similar trunks for HIV/AIDS, tuberculosis and other major public health diseases—if indeed this has not already been done].

RELEASE, International Nepal Fellowship

We are grateful to Dr Friedbert Herm, Release Medical Advisor, and Shailendra Gautam, Acting Programme Manager, for their report of the Leprosy Control Programme for the year 2000. The background reads as follows:

The International Nepal Fellowship

The International Nepal Fellowship (INF) is an International Non-Government Organisation (INGO) working in Nepal. For nearly 50 years, INF has been working with His Majesty's Government and the people of Nepal to improve the health and develop the health services of the country. INF seeks to be a partnership, supplying expatriate specialists to work with and for Nepali nationals in different projects, mainly in the Western and Mid Western Regions of Nepal.

RELEASE

RELEASE is one of the five projects of INF. Working predominantly in the Western Region, RELEASE includes four inter-dependant programmes. All of the programmes are focused on holistic healthcare and rehabilitation. They work through different mixtures of service provision, training, networking, community mobilisation and advocacy. The Leprosy Control Programme (LCP) supports anti-leprosy treatment and prevention of impairment and disability activities through the government health system. Green Pastures Hospital (GPH) provides tertiary referral and rehabilitation facilities for people disabled by any cause, but especially those with complications due to leprosy or other neuro-disabilities. Partnership for Rehabilitation (PFR) offers social and economic rehabilitation, skills training and income generation support primarily for those affected by leprosy, their families and communities in order to help them to improve their own quality of life. The Drug Rehabilitation and AIDS Programme (DRAP) offers detoxification and rehabilitation for drug misusers, works to prevent HIV infection, and provides psycho-social support for people who are infected or affected by HIV/AIDS. All four programmes receive administrative and technical support from the Project Office (PO).

This report documents the activities of the Leprosy Control Programme throughout 2000. Technical data are for the Nepali fiscal year (July 1999–July 2000). Other reports are available from RELEASE for the remaining programmes of the project.

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News and Notes

LEPRA in the 21st Century

On the occasion of the Annual General Meeting of LEPRA in London in July, 2001, copies of the *Report and Financial Statements* were available, describing in detail the income, expenditure, main activities and future plans of the Association. The Report included the following information on objectives, policies and activities.

OBJECTIVE OF THE ASSOCIATION

The main objective of the Association is to carry out the investigation of and promote research into the causes, treatment, cure and prevention of the disease of leprosy and any allied disease, and give and grant relief and assistance to any person suffering or believed to be suffering therefrom, or the family or dependants of such persons of any description, including financial assistance. (Extract from the Memorandum of Association).

This year 2000, the beginning of the new millennium, started with so much promise on the one hand, and concern on the other! There was certainly a widespread feeling of 'new beginnings' and a belief that there would be countless new opportunities. Such feelings certainly turned out to be correct for LEPRA. There was, of course, concern about the millennium 'bug' about which so much was written but did not in fact, appear to live up to expectation, and one wonders about the amount of resources that were used unnecessarily. Indeed, at the beginning of the year, we were talking about the forgotten 'bug' which causes leprosy and how much could be achieved towards the total eradication of the disease if only part of what was being spent on the millennium bug could be used in the fight against such a terrible disease.

The Director, Terry Vasey, in his role as President of the International Federation of Anti-leprosy Associations (ILEP), was deeply involved in the newly formed Global Alliance for the Elimination of Leprosy. The Alliance, launched in Abidjan in November 1999 consists of Governments of leprosy endemic countries, the World Health Organisation (WHO), the Nippon Foundation of Japan, Novartis, ILEP, the World Bank, and Danida. The Head of Programmes, Doug Soutar continued in his role as Chairman of the ILEP action group on Teaching and Learning materials in leprosy, and Tilak Chauhan, the Chief Executive of LEPRA India took on the role of Convenor of the ILEP representatives in India. Of course, it is India where the greatest number of new cases of leprosy is found and consequently where those suffering from the after effects of it are also found.

In India Dr K. V. Desikan, the Chairman of LEPRA India, won the prestigious Damien Dutton Award for his 50 years of service and dedication in the fight against leprosy. The end of the year saw the announcement that he would receive the International Gandhi Award in February 2001.

We believe that such high profiles and esteem in which LEPRA is held are the result of the quality of work that we undertake and support in the field. Our principal objective, written almost 80 years ago remains 'To carry out the investigation of and promote research into the causes, treatment, cure and prevention of the disease of leprosy and allied diseases...'. It is with pleasure we report therefore that once again our income increased by 22% over 1999 allowing us to plan further expansion and commence new initiatives.

Members of the Executive Committee met with members of its Medical Advisory Board and staff from England and India to plan our longer term strategies which resulted in a new commitment to growth and the broadening of our scope whilst retaining leprosy as our central focus. Vertical leprosy control programmes are at last being incorporated into general health services in many countries and general health care staff need training and support. In order to be cost effective in providing specialist services to those affected by leprosy we intend to follow our original mission to fight allied diseases such as tuberculosis, HIV infection, lymphatic filariasis, malaria and leishmaniasis wherever appropriate.

POLICIES OF THE ASSOCIATION

LEPRA's policies are that:

High quality services are given to patients through the running and support of leprosy control programmes.
Medical research into the causes and cure of the disease of leprosy and allied diseases is undertaken.
Governments are assisted to integrate services to leprosy patients into local health services or, at least, to combine them with TB control and HIV awareness raising programmes.
High priority is given to prevention of disability in all programmes.
Surgical and, where possible, socio-economic rehabilitation programmes are undertaken.
Medical Consultancy and Advisory Services are continued.
LEPRA continues to publish Leprosy Review, LEPRA's scientific journal.
High quality Training Programmes are run in all LEPRA supported programmes.
Education and Awareness Raising Programmes are run in all programmes which LEPRA supports, including the United Kingdom.
LEPRA will establish closer working relationships with Governments and Non Governmental Organisations at both local and international levels.
All assistance is monitored and evaluated to ensure the highest quality of service is maintained.
LEPRA will fight allied diseases, such as tuberculosis, HIV infection, lymphatic filariasis, malaria, and leishmaniasis wherever appropriate.

CHARITY ORGANIZATION

Her Majesty, Queen Elizabeth II, is Patron of the Charity and Sir Christian Bonington CBE, is President. Vice Presidents are HRH The Duke of Gloucester GCVO, The Secretary of State for Foreign and Commonwealth Affairs, Mr G. F. Harris, MC OLM, Baroness E. Nicholson of Winterbourne and Mrs N. K. Trenaman. The organisation of the Charity consists of a Chairman, Board of Trustees, Hon. Treasurer and Secretary who is the Director.

REVIEW OF ACTIVITIES

Based on our current available data we helped fund projects worldwide covering a total population of 270,474,319 and where 70,501 new cases of leprosy were detected. This means that LEPRA gives support to 10·4% of all projects supported by the International Federation of Anti Leprosy Associations (ILEP) and in those projects supported by us 19·9% of all new cases are found. (These figures exclude our assistance to the Prevention of Disability Programme in China which covers a population of 88 millions).

As planned our funding of the field activities we supported in 1999 continued in 2000 with increased expenditure in our direct programmes of India, Mozambique, Brazil and Bangladesh. In India we purchased 10 Health Education vans in order to broaden our coverage and efficacy in this area.

Funding to Mozambique included a £50,000 emergency grant, which was sent to assist after the terrible flooding there.

Our Social and Economic rehabilitation programmes were extended to all our projects in India and over 9,000 people affected by leprosy were helped.

Eye care was included in more projects and increased numbers of cataract operations were carried out as well as eye surgery inserting intra ocular lenses to restore sight.

We established technical support teams in the three Indian states of Andhra Pradesh, Bihar, and Madyha Pradesh. As an example two teams in Madyha Pradesh will cover a population of 5·2 millions and in Bihar a population of 11·7 millions will be covered.

The joint TB/leprosy programme in Orissa, India was extended to cover a whole district in conjunction with DANTB and Government and our new offices in Orissa opened as planned.

The Blue Peter Research Laboratory was equipped and research in TB, leprosy, and HIV started there in January 2000.

The Healthy Highway Project, which is funded by the Department for International Development, continued and will be further extended. This project is aimed at reducing the spread of sexually transmitted diseases, including HIV, amongst truck drivers and commercial sex workers in India.

The formal registration procedures of our offices in Brazil and Bangladesh were completed, and all staff in Bangladesh are now in post. Our representative in Brazil has been able to employ an administrator which will enable him to give more support to projects and seek out new initiatives. The registration also allows for easier transfer and utilisation of funds.

Our support to the National Leprosy Programme in Madagascar continued, however our French colleagues did not need the extra inputs we had anticipated.

A second World Bank loan to the Indian Government for leprosy control took longer than anticipated, and LEPRA India's accountant was asked to assist the Government in drawing up its budgets as well as working closely with the Government of Orissa to prepare its own future plans.

Our contribution to the research programme in the Karonga District of Malawi continued and the Wellcome Trust is considering funding a new programme of research to be carried out there.

We supported a programme in Tamil Nadu India, working with lymphatic filariasis.

Future activities

The focus of LEPRA's growth in 2001 will be the continued expansion of our activities in India, Brazil, Mozambique and Bangladesh.

In India we will be providing 15 technical Support Teams in four states and will begin work with three new partner NGOs in Andhra Pradesh, Bihar and Maharashtra. New work in Orissa will be facilitating the effective integration of leprosy work into the Primary Health care system and will include work in the Bargarh District, which is one of the most endemic districts in India. We will also provide support for a state level Sample Survey Assessment Unit in Andhra Pradesh which will help monitor the effective implementation of the national leprosy elimination programme in that state.

We will establish support for patient advocacy groups in four states in north eastern Brazil and consolidate our new programmes in Bangladesh.

We will support new leprosy and TB initiatives in Angola and investigate opportunities for supporting work in other priority countries such as Myanmar, Nepal and Madagascar.

The Executive Committee has carefully considered and is able to confirm the adequacy of the Charity's assets to fulfil its future obligations.

Bombay Leprosy Project

Reports are available on two Silver Jubilee Year commemorative functions held by the Bombay Leprosy Project.

Computer training for the disabled

Bombay Leprosy Project started its computer training courses on 3rd July in collaboration with the Sion branch of St Angelo's Computer Ltd. The course was inaugurated by Mr Mangesh D. Karangutkar, a handicapped individual, at a simple but meaningful function organized to commemorate the Silver Jubilee Year of BLP.

The first batch of five trainees, which includes a leprosy disabled person from Dharavi slum, is being fully sponsored by BLP, through funds raised from the public for the 3-month course. BLP plans to recruit many more handicapped individuals for future training courses, depending on the level of public donations.

Seminar on pathogenesis of early leprosy lesions

As a consequence of the country-wide efforts to identify at the earliest possible stage when the disease takes root, the National Leprosy Eradication Programme is confronted by problems related to diagnosis of early leprosy, which is the commonest form of the disease currently encountered in leprosy endemic regions in the world.

How does the pathogen causing leprosy gain a foothold in the skin and nerves? How does the human host react to invasion by this pathogen? How can leprosy be diagnosed with certainty at the earliest stage?

These questions were debated on Tuesday 3rd July at the Sion Medical College by a team of experts from the Bombay Leprosy Project and the faculties of dermatology and pathology, following an elaborate and painstaking review of the subject by postgraduates of K. J. Somaiya Medical College. The seminar was organized by BLP in commemoration of its Silver Jubilee Year.

The animated discussions revealed the need for focused research on early leprosy by collaborative efforts to try and find satisfactory answers to the questions raised in this seminar.

Gandhi Memorial Leprosy Foundation, India

We are grateful to Dr V. V. Dongre, Director, GMLF, Wardha 442001 Maharashtra, India for a copy of The Annual Report 2000–01, 'Golden Jubilee Year'. His Epilogue reads as follows:

> On 6th December, 2000, GMLF has entered its 50th year of existence. Longevity is a curse for an organization that works for controlling a communicable disease. Nonetheless, continuation of efforts to control the disease is noteworthy.
>
> In the last 49 years, the Foundation has paved the way towards elimination of leprosy. It has done pioneering work in the initial years when NLEP was born. It has influenced the lives of hundreds and thousands of leprosy patients and leprosy workers. The genesis of Survey, Education and Treatment (S.E.T.) pattern, involvement of General Medical Practitioners in the programme, training of Paramedical Workers, concept of Referral Hospitals, realizing importance of Health Education in the programme, motivation for political will and advocacy for the allied organizations and relatively late included Social Science Research are some of the landmarks of the Foundation's work.
>
> This was possible because of the devotion of a band of staff members and the foresight of the earlier path-finders.
>
> As it happens in almost every very well established organization, the output of good work of GMLF remained on a plateau for some time and then declined rapidly. The organization that was a grantor became a grantee organization. Good workers deserted the Foundation due either to its step-motherly attitude towards them or for green pastures. The result naturally was not unexpected in this situation. An organization does not consist of brickbats and walls alone. The workers are the soul of it. When that is at stake, providence is in peril!

Outside the Foundation, the circumstances have changed drastically. Leprosy has not remained a priority from many points of view. Foundation did not mould its policies accordingly. However, today, it is heartening to know that those workers who left the Foundation, are coming forward actively to rejuvenate its activities. This will happen as long as it is needed. Therefore, needless to say, the Foundation will bear the torch for leprosy elimination as long as it is required to be carried out.

Leprosy: the case of the missing genes

The following is taken from Issue 26 Q1 2001 of *Wellcome News* (Research and Funding News from the Wellcome Trust), 183 Euston Road, London NW1 2BE, England (Fax +44 (0)20 7611 7288):

> Scientists at the Wellcome Trust Sanger Centre and the Pasteur Institute in Paris have published the genome sequence of *Mycobacterium leprae*, the cause of leprosy. They have also compared the sequence, published in *Nature*, with that of its relative, *Mycobacterium tuberculosis*, which causes TB.
>
> The comparison threw up some startling differences. *M. leprae* has just 1600 genes (*M. tuberculosis* has 4000) and many of these are non-functional 'pseudogenes'. *M. leprae* also seems to have lost most of a large family of *M. tuberculosis* genes that direct its interaction with its human host. The genetic differences between the two species are reflected in their differing biologies, as *M. leprae* survives in a much more narrow environmental niche—it lives only in the human peripheral nervous system.
>
> The sequence should open up new ways of tackling leprosy, a disease that affects more than a million people a year. As with all projects at the Sanger Centre, DNA sequence information is released onto the Internet without restriction or charge to users. The project was funded by the Heiser Trust (Heiser Program for Research in Leprosy and Tuberculosis of The New York Community Trust), l'Association Francaise Raoul Follereau, the International Federation of Anti-Leprosy Associations (ILEP, which includes LEPRA in the UK), the Pasteur Institute and the Wellcome Trust.

The relevant article is entitled 'massive gene decay in the leprosy bacillus' by S. T. Cole *et al.* in *Nature*, Vol 49, 22 February 2001, www.nature.com and the summary reads:

> Leprosy, a chronic human neurological disease, results from infection with the obligate intracellular pathogen *Mycobacterium leprae*, a close relative of the tubercle bacillus. *Mycobacterium leprae* has the longest doubling time of all known bacteria and has thwarted every effort at culture in the laboratory. Comparing the 3·27-megabase (Mb) genome sequence of an armadillo-derived Indian isolate of the leprosy bacillus with that of *Mycobacterium tuberculosis* (4·41 Mb) provides clear explanations for these properties and reveals an extreme case of reductive evolution. Less than half of the genome contains functional genes but pseudogenes, with intact counterparts in *M. tuberculosis*, abound. Genome downsizing and the current mosaic arrangement appear to have resulted from extensive recombination events between dispersed repetitive sequences. Gene deletion and decay have eliminated many important metabolic activities including siderophore production, part of the oxidative and most of the microaerophilic and anaerobic respiratory chains, and numerous catabolic systems and their regulatory circuits.

A Commemorative Issue, Supplement 4, of *Wellcome News*, entitled 'Unveiling the human genome', first draft 2001, was published earlier this year, providing (to quote from the Director's covering letter) '... brief descriptions of the human genome and some of its more fascinating features, the history of the Human Genome Project, how sequence data can be used and the ethical and social implications of the research.

The contribution of dermatological clinics to leprosy control in the People's Republic of China

In this issue an article by Chen Shumin and colleagues will be published on the prevention of disability in leprosy patients in Shandong Province, the People's Republic of China. This includes mention of the continuing cooperation between the leprosy services and the dermatologists working in dermatological clinics. In fact, over one-third of all new cases in PR China have been detected in such clinics in recent years, underlining the very considerable contribution of dermatology to leprosy diagnosis and control in this country—an unusual situation in other leprosy-endemic countries, even when dermatologists are available. See recent contributions on this subject on the *Leprosy Mailing List*, Cefpas, Caltanisetta, Italy. E-mail: noto@cefpas.it

Leprosy mailing list (e-mail) from Cefpas, Caltanisetta, Italy

Dr Salvatore Noto at the Centre for Research and Training in Public Health (Cefpas), Via G. Mulè, 1, 93100 Caltanisetta, Italy, has established a 'Leprosy Mailing List' for the exchange of information between people working with this disease, using e-mail. From a modest beginning, the list now has dozens of names from correspondents in control, research, public health, communications, dermatology, charities, tuberculosis and publishing, etc. We congratulate Dr Noto on this potentially very valuable initiative. *Further information*: Cefpas: fax +39 0934 594310. http://www.cefpas.it e-mail: cdf@infoservisi.it

OCEDUS: observatory of the European citizenship for human rights, Caltanisetta, Italy

Within Cefpas (Centre for Training and Research in Public Health), OCEDUS is being launched, with the following objectives:

- To develop a European culture for the promotion of human rights and health conditions and, thus, to ensure peoples' welfare through the understanding and respect of the fundamental rights sanctioned by the UN and the EU.
- To create a Permanent International forum to discuss and find solutions to the serious problems of human, animal and environmental health caused by human rights violation.

The main objectives are:

- To collect data, to develop research and training activities and to disseminate knowledge for the promotion of human rights.
- To organize meetings, debates, discussions at international level so as to find concrete answers to the problems regarding human rights violations and their effects on health.
- To create a world-wide telecommunication network for the rapid exchange of information on the subject.

Further information: Cefpas, Citadella Sant'Elia, Via G Mulè, 1, 93100 Caltanisetta, Italy. E-mail: ocedus@cefpas.it

WHO 'Leprosy Elimination Kit'

We have recently received copies of the following three documents from WHO:

1. Guide for Health Professionals to Eliminate Leprosy as a Public Health Problem who/CDS/CPE/

CEE/2000.14. Developed in collaboration with the Global Alliance for Elimination of Leprosy: member States of the World Health Organisation, Danish International Development Assistance (DANIDA), International Federation of Anti-Leprosy Associations (ILEP), Nippon Foundation, Novartis Foundation for Sustainable Development and World Health Organisation. 38 pages, A5 format.

2. Guide for Information, Education and Communication for Elimination of Leprosy. Communication Concepts and Support Material. 36 pages, A3 format. Highly illustrated in colour. Wide range of '... templates for approaches to communication about leprosy ... for modification and adaptation to local conditions and cultures ...'
3. How to Monitor Leprosy Elimination in your Working Area. WHO/CDS/CEE/2001.19. Main headings—The Final Push to Eliminate Leprosy; Why do we Monitor?; Elimination Indicators, Patient Care Indicators; Managerial Indicator.

Further enquiries: Leprosy Elimination Group, World Health Organisation, CH-1211 Geneva 27, Switzerland. Internet: www.who.int/lep E-mail: ee@who.int Fax +41 22 791 48 50.

TDR: A massive effort against diseases of poverty: What role will research play?

This is the title of the Keynote Article in the February 2001, Number 64 issue of *TDR News*, written by David Heymann, Executive Director of the Communicable Diseases Cluster at WHO and David Nabarro, Executive Director In the Director General's Office. It reads as follows:

> A WHO-led massive effort against diseases of poverty (announced in October 2000) is a process that is primarily about prosperity and strengthened health delivery systems, not about diseases. It is about people and how to improve their health, about health systems and how they respond to poor people. It is about getting well-tested and effective control interventions to the people who need them, whether by reducing their costs, improving their distribution, increasing their efficacy, or slowing down the development of antimicrobial resistance. Such a massive effort would involve a whole range of partners from public, private and not-for-profit sectors, bringing focus to the disconnection in what we actually do and what we would like to do in terms of controlling the diseases of poverty.
>
> A massive effort would eventually make available a sustained high level of resources that would make possible both increased access to existing drugs, vaccines and diagnostic tests, and research to better use these existing goods and develop the new ones necessary.
>
> What is the place of research in this effort? Disease control today depends on cost-effective strategies to best use the many drugs, vaccines and diagnostic tests that, when used properly, are capable of reducing mortality. But, today these strategies don't reach all who need them, and maybe we can develop better strategies. So the massive effort will, in part, be about developing better strategies to make existing drugs, vaccines and diagnostic tests more accessible to those in need (e.g. the use of bednets in Africa would need to be scaled up 20 times using strategies that ensure better access and increase demand). Operational research is therefore required in a massive effort.
>
> With evidence in the form of data from well-designed operational research and its analysis and synthesis, we can demonstrate that existing interventions get drugs, vaccines and diagnostic tests to where they are needed in a way such that they can be maximally used.
>
> At the same time, research in a massive effort is also required to develop new tools—new drugs and vaccines, and easier-to-use diagnostic tests. Adaptations of existing products, such as better fixed-dose combinations of drugs for tuberculosis and malaria, simplified for field use, are also required.
>
> TDR, with its broadened disease mandate and new emphasis on operational research, is well placed to ensure the research necessary for a massive effort. As increased funds for a

> massive effort become available, the balance between funds used to make existing vaccines, drugs and diagnostic tests available, and funds for operational and more basic research and development, will be a great challenge. TDR has successfully maintained the correct balance between research and implementation in the past, and will surely rise to the task of doing the same as a massive effort continues to evolve.

TDR increases its efforts in social, economic and behavioural research

This article, under the heading of Basic and Strategic Research, appears in the latest issue, No 64 of TDR News, February 2001:

The new Steering Committee on Strategic Social, Economic and Behavioural Research (SEB) issued its first call for grant applications in October 2000. Over the next 2–3 years, SEB will focus on supporting research that increases understanding of:

- how large-scale social and economic forces affect inequality of access to treatment, prevention and information related to infectious diseases;
- the implications of globalization on the persistence, emergence and resurgence of these diseases.

Studies of this nature will require innovative research methods, involving multi-level analyses that allow for investigation of the effects of large-scale forces on local level processes and outcomes. An important aspect of the Committee's work will be to support capacity building to conduct such analyses.

From the beginning, TDR has placed considerable emphasis on the social and economic aspects of tropical infectious diseases and their control. From 1979–94, TDR supported social science research through its Steering Committee on Social and Economic Research (SER), and since 1994, applied social science research has been supported by the Intervention Development and Implementation Research team (formerly the Applied Field Research team).

In June 1999, TDR's Joint Coordinating Board (JCB) approved the creation of a new Steering Committee on Strategic Social, Economic and Behavioural Research (SEB). As mentioned in *TDRnews* No. 63, SEB is located within the Basic and Strategic Research team (STR) to reflect its focus on basic social, economic and behavioural research issues of trans-disease and global importance.

A Scientific Working Group (SWG) of experts from a range of social, economic and policy sciences met in Geneva in June 2000 to set the overall direction for SEB. In September, the SEB Steering Committee met for the first time, and developed a vision for the next five years and a detailed workplan for the coming two years.

The focus of SEB reflects WHO's growing interest in the complex relationship between poverty and health. On a worldwide scale, infectious and parasitic diseases disproportionately affect populations living in poverty. Social, political and economic inequalities are central to the persistence and spread of these diseases, and the performance of health systems in protecting vulnerable populations from the impact of these diseases often falls far short of potential. Over the next several years, the SEB Steering Committee will examine these issues within the context of globalization, the changing role of the state, and the emerging role of non-state actors (the private sector, NGOs and civil society).

Repositioning of leprosy in TDR: notice to leprosy researchers

From TDR News (UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases) No 64, February 2001:

> In December 2000, Carlos Morel, Director TDR, and Bjorn Melgaard, Director WHO Department of Vaccines and Biologicals, agreed that leprosy research previously under the purview of the TDR Steering Committee on Immunology of Mycobacterial Diseases

(IMMYC), will in future be integrated into each of the four functional areas of TDR: Basic and Strategic Research (STR), Product Research and Development (PRD), Intervention Development and Implementation Research (IDE), and Research Capacity Strengthening (RCS). This move brings leprosy into line with all the other diseases in TDR's mandate, which have been addressed by the functional units since 1994, and it will make TDR leprosy research more sustainable. Dr Paul Nunn, in his position as TDR Leprosy Disease Coordinator, will coordinate TDR activities with each of these area. Researchers are invited to submit proposals directly to each areas according to their deadlines.

Additional information on research grants as well as application forms: www.who.int/tdr/grants

INASP-Health, UK

INASP-Health is a cooperative network created by health information providers, for health information providers. Its goal is to facilitate co-operation across the health information community towards universal access to reliable information for health professionals in developing and transitional countries.

The network currently involves more than 600 participants. North and South, representing non-governmental organizations, international agencies, library services, publishers (print and electronic), and others. Visit our website at: www.inasp.org.uk for further information about our range of services and activities.

We welcome all those who are willing to share their experience and expertise with others to improve access to reliable information. Participation is free of charge and without obligation. Please write to:

Dr Neil Pakenham-Walsh
Programme Manager
INASP-Health
27 Park End Street
Oxford OX1 1HU, UK

Please note, new telephone number for INASP-Health!

Tel: +44 (0)1865 248 124
Fax: +44 (0)1865 251 060
E-mail: ⟨INASP_Health@compuserve.com⟩
WWW: ⟨www.inasp.org.uk⟩

'INASP-Health in association with WHO, runs the HIF-net at WHO' which links 500 people worldwide-health professionals, librarians, publishers, technologists, policy-makers on an e-mail list dedicated to the improvement of reliable, relevant information for health professionals in developing and emerging countries.

The Wellcome Trust, London, UK: Grants Handbook 2000

The Grants Handbook 2000 (70 pages) begins with following Introduction:

With an asset base of £13 billion and an annual expenditure of more than £450 million, the Wellcome Trust is the world's largest medical research charity. Its mission is 'to promote and foster research with the aim of improving human and animal health'. The Trust funds most areas of biomedical research, although its support for cancer research is limited.

The Trust supports basic, 'blue skies' research as well as studies of direct medical relevance. Its funding schemes are similarly diverse, covering support for research centres, individual programmes and projects, scientific equipment, international collaboration and exchange, and research infrastructure.

It runs personal support schemes covering all stages of the research career, from PhD studentships to Principal Research Fellowships (which are reader professional-level fellowships).

The Trust is committed to providing scientists with the resources and support they need to carry out world-class research. As well as investing in the UK university research infrastructure, it has been increasing its long-term support—for example, through programme grants and long-term fellowships. The Trust is also committed to improving the salary conditions of academic researchers and has always striven to facilitate the development of scientists whose careers have needed, for a variety of reasons, to be flexible. The Trust is willing, in all its schemes, to accept applications from individuals wishing to work part time, returning to science or undergoing career reorientation.

The Trust supports excellent science all over the world, and is a major supporter of research in the developing and restructuring world. Its activities there focus on the diseases of the tropics (infectious and noninfectious), the medical impact of population change, and international collaboration and exchange. It funds research in its own Overseas Units, in Kenya, South-East Asia and South Africa, and in other overseas centres of excellence.

The Trust has made a substantial investment in genome sequencing, primarily at the Sanger Centre on the Wellcome Trust Genome Campus at Hinxton, near Cambridge. The Sanger Centre is one of the largest single contributors to the Human Genome Project, the global collaborative venture to sequence the 3 billion nucleotides of the human genome. It is also one of the world's leading centres for the sequencing of genomes of microbial pathogens, having sequenced *Mycobacterium tuberculosis* (TB), *Campylobacter jejuni* (food poisoning), and *Neisseria meningitidis* (meningococcal septicaemia), among others.

The Wellcome Trust is committed to developing partnerships with other governmental and nongovernmental bodies that share its commitment to biomedical research. The £750 million Joint Infrastructure Fund, a partnership with the UK Government, was launched in 1998 to alleviate the research infrastructure crisis in UK universities. The Trust has entered into several other joint funding agreements with the governments of other countries and with other charities in the UK and overseas.

The Trust also makes other significant investments in the biomedical science base. Most notable is a £110 million commitment to a new synchrotron facility in the UK. Moreover, the Trust's funding policies are continually being assessed, to ensure that the Trust remains responsive to scientific opportunities and medical priorities. It is currently developing major new funding initiatives arising from the Human Genome Project.

While research can provide profound insights into the natural world, its full worth is gained when it is applied to improve human health more directly. The Wellcome Trust has established a business subsidiary, Catalyst BioMedica Ltd, to help ensure that promising lines of research do lead to medically useful products or services. Catalyst works in partnership with Trust-funded researchers, university technology transfer staff, financial institutions and the pharmaceutical industry to identify and exploit research opportunities. It advises on the protection of intellectual property, helps to negotiate commercialization agreements and has a development fund for progressing applied research with the potential for improving healthcare.

The Wellcome Trust's Medicine, Society and History activities provide a historical and social counterpoint to its medical research funding work. Founded on the principle that today's medical research is poised to have a significant impact on society, the programme aims to engage the public in informed debate about biomedical research and its medical application, inform public policy making in this area, and to ensure that the valuable lessons of history inform and influence current debate.

The Trust's grant-giving activities in this area include a comprehensive range of schemes for support of research in the history of medicine—the Trust is the UK's biggest funder of historical medical research. The Medicine in Society funding programme is exploring the social, ethical and public policy implications of developments in medical science; its areas of interest encompass biomedical ethics and public engagement with science, and it provides support both for academic research in this area and for public communication projects.

The Handbook carries detailed information on policy and funding decision making: grant decision-making processes: applying for support: information for applicants: overview of funding opportunities. *Apply* Grants Information Department, The Wellcome Trust, 183 Euston Road, London NW1 2BE. E-mail: grantenquiries@wellcome.ac.uk

Susceptibility to infection

This is the title of a Clinical review in the *British Medical Journal*, volume *321* of 28 October 2000, pages 1061–64.

The opening paragraphs read as follows.

Genetic factors explain, at least in part, why some people resist infection more successfully than others. Rare gene disruptions cause fatal vulnerability to specific microbes, but more subtle differences are common and arise from minor variation in many genes. Recent advances in the human genome project and in high throughput genotyping technology will make it feasible within the next decade to screen the whole genome for genetic factors that determine susceptibility to HIV and AIDS, malaria, and tuberculosis. This will help to identify critical pathways of host defence and generate novel strategies for disease prevention. Understanding the evolutionary impact of infectious disease on the human genome may shed light on the origins of other common diseases, particularly those with an atopic or autoimmune component.

Historical accounts of the plague tell of individuals who survived unscathed in households where almost everyone else died. Each winter, British hospital wards are full of infants requiring oxygen therapy for bronchiolitis, but most infants infected with the same virus have little more than a runny nose. Over a million African children die each year of malaria, but many more remain in relatively good health despite being continually infected with the parasite.

To what extent does our genetic make up determine the different ways that we respond to the same infectious agent? This is difficult to answer because of the many other contributory factors involved, such as previous health, acquired immunity, and variability in the pathogen. Epidemiological analysis of the genetic component is confounded by environmental factors that cause familial clustering and is further complicated by the many different genes that are likely to be involved. Nevertheless, there is compelling evidence for a genetic component, including twin studies of tuberculosis, leprosy, malaria, and *Helicobacter pylori* infection and a large survey that found that individuals adopted in childhood had a markedly increased risk of death from infection if a biological parent had died prematurely of infection.

Unravelling the genetic and environmental determinants of infectious disease will soon be feasible. The human genome sequence provides the starting point for a systematic analysis of human genetic diversity (www.wellcome.ac.uk/en/genome). The most common form of DNA variation is a direct swap of one nucleotide for another, such as adenine for guanine, known as a single nucleotide polymorphism or SNP (pronounced 'snip'). Polymorphisms that are present in at least 1–2% of normal individuals are found on average once in every 300–600 nucleotides, suggesting that some 10 million may be present across the whole genome. Although only a small proportion of these polymorphisms may be of functional relevance—by causing disruption or structural alteration of the protein encoded by a gene or by altering neighbouring regions of DNA that control gene regulation—all are of potential value as genetic markers for mapping regions of DNA that determine disease susceptibility. Much work is going into the development of DNA chips and other novel technologies for high throughput typing of single nucleotide polymorphisms that will make it feasible to screen many thousands of these markers in large study populations, with the ultimate goal of mapping disease associations across the whole genome. Efforts are being made to assemble the large DNA collections that will be required for this complex exercise.

What is the practical purpose of understanding the molecular genetic basis of susceptibility to infection? Efforts to develop vaccines and improving treatments for major diseases such as tuberculosis,

HIV infection and AIDS, and malaria are hindered by our poor understanding of the molecular and cellular mechanisms that determine clinical outcome. Genetic epidemiology may identify hitherto unknown molecular mechanisms and improve understanding of critical events in the evolution of disease. For example, if an infectious disease is associated with high levels of a factor X in the blood, it is often difficult to know whether this is of pathogenic importance or simply an epiphenomenon of the disease process. But if the production of X is known to be determined by a genetic polymorphism, and if this polymorphism is shown to predispose to the disease in question, then there is a much stronger case for X playing a causal role.

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Instructions to Authors

Article submission. Articles submitted for publication in Leprosy Review should be sent to the Editor at the following address: Diana Lockwood, LEPRA, Fairfax House, Causton Road, Colchester CO1 1PU, England. The name(s) of the author(s) and the place where the work was done should be indicated clearly below the title of the article. Degrees and diplomas are not to be included.

It is understood that the article is offered to Leprosy Review alone, that it will be subject to editorial revision, and that its copyright becomes the property of LEPRA.

Format. Articles must be submitted *double spaced*, on one side of A4 (297 x 210 mm) paper, with wide margins (4 cm all round) in triplicate. On a separate sheet give the title, short title, name and postal address of the author, together with the name of the institution where the work was done. Abbreviations of titles of journals should follow the list of journals indexed in Index Medicus. References to books should include the editor(s), publisher and place of publication.

Electronic submission. Articles produced using a word-processor should also be supplied in electronic format (preferably Word or Wordperfect 5.1) if possible. Please submit a disk with the final revised version of the article. The electronic file should correspond exactly to the hard copy.

References. References should follow journal style [please contact the Assistant editor (e-mail sboobis@aol.com) for guidance if required], and journal title abbreviations should follow Index Medicus. Incorrectly styled references may lead to delay in publication.

Illustrations and Tables. Contributors must send the original artwork and two copies on separate sheets. In addition electronic versions may be submitted in the form of compressed tiffs, eps, jpegs or bitmaps. The recommended resolution is 600 dpi or above.

Units and Abbreviations. The journal recognizes the adoption of the Systeme International d'Unites (SI Units) proposed in Units, Symbols and Abbreviations (1972) published by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. Abbreviations should only be used for unwieldy names, and only when they occur frequently.

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