

Antileprotics, Leprosy and the Profession

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Despite the widespread dissemination of information and availability of improved technologies, progress in leprosy control over the past 10 years has been disappointingly slow. Part of this is due to continuing inadequacies in the training of all levels of health workers. The structure of Nepal's leprosy control programme is briefly outlined and the drug treatment and major problems in the disease are described. The role of the doctor in leprosy control is discussed followed by his continuing education and familiarisation with the many problems in leprosy. Some suggestions are put forward regarding improving the service provided for leprosy patients.

INTRODUCTION

In the past forty years leprosy has been transformed from a fearful, untreatable scourge with inevitable progression towards terrible deformity to an eminently treatable infectious disease with a hope of global eradication. In Nepal, as in virtually all leprosy endemic countries, the objectives of leprosy control have been clearly stated and are accepted. The methods are well defined, are currently the national policy and are being put into practice, to a greater or lesser extent throughout the country. The key activities required are well described, understood, agreed-upon and being carried out. Multiple drug therapy is widely available and increasingly, more leprosy patients are receiving this new standard form of therapy.¹ This inspiring situation is, however, a reflection of theory, policy and goals. There is a large gap between words and action.² The truth of the matter is that despite the above description,

leprosy is not on the decline. There is still an unacceptable depth of ignorance about this disease, as well as with so many other public health problems, in the community. There is often still a long delay between the first symptoms of the disease and the patient seeking help from allopathic health services. There is often a long delay before correct diagnosis and management is instituted. All too often, complications of the disease, most notably neuritis with nerve function deterioration, are not promptly identified and treated. There are still far too many patients on inadequate treatment.³ Even in Nepal many do not receive multiple drug treatment (MDT), but continue to take a form of treatment which was condemned over 10 years ago as being hazardous on account of the dangers of resistance.⁴ One of the major reasons for the absence of satisfactory progress in leprosy control is the poor level of awareness about leprosy in health workers. This is a problem common to all continents where leprosy is

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found and common to all levels of health workers whether it be academics in capital cities, private practitioners in provincial towns, medical auxiliaries in hospital and health post out patient departments or community health workers in the field. A survey of 106 medical schools in India revealed that the average time spent on leprosy during the whole undergraduate curriculum is only four and a half hours.⁵

This is felt to be about the same in Africa and doubtless elsewhere. There has been some international concern about this shortcoming and the major need is felt to be for teaching and learning materials, better coordination and access to resource information.⁶ In many parts of south east Asia, the doctor in the hospital outpatient department or the private practitioner in his surgery is providing primary health care and may be the first line of contact between a leprosy patient and competent health services. It is therefore essential that in these areas of endemic leprosy, the practitioner is fully aware of the necessary simple procedures required to establish a certain diagnosis, assess the degree of damage and prescribe accordingly. Appropriate health education and where necessary, examination of contacts should also be provided. It is clear that four and a half hours is totally inadequate to provide this and hence more input is required during the basic training as well as after qualification. A reasonable knowledge of the structure of the programme and the facilities available will enable the practitioner to provide the best services for his patients.

THE LEPROSY CONTROL PROGRAMME

For many years there had been strong central management of leprosy work in Nepal, coordinated by the Leprosy Control Project and supervised by the Leprosy Services Development Board. With integration of vertical programmes this has now become the Leprosy Control Section of the Public Health Division. This central unit did much in the early days of leprosy treatment to raise the level of awareness about leprosy in

Government circles, within the Ministry of Health and among the people. With the assistance of several non-governmental organisations (NGO's), clear areas of responsibility were allocated and to a great extent duplication of services has been avoided. In most of the five development regions of Nepal there is now a well-established partnership between one of these NGO's and the Government health services but inevitably the style of each region's leprosy programme defers slightly. The basic principles, however, are the same and are clearly outlined in the manual produced by the International Nepal Fellowship in 1985.⁷

This describes the structure of the programme, gives treatment regimens recommended by the Ministry of Health and being implemented by them and the NGO's, outlines the job descriptions of different cadres of worker in leprosy control and deals in detail with the implementation of MDT. At present Nepal's programme could best be described as semi-integrated. The national policy of the provision of primary health care through integrated health services has, in most regions, been gradually implemented to the extent that leprosy patients are increasingly being regularly attended by the multi-purpose health post staff (health assistant, auxiliary health worker and assistant nurse midwife) at the health post closest to their home. On leprosy clinic days a leprosy supervisor or leprosy paramedical worker, who is responsible for the district, will usually visit the health post and ideally the local workers and visiting district worker should see the patients and deal with their problems in a team atmosphere. Sometimes this system works.

Although not identical to other regions, the pattern in the eastern terai districts demonstrates this straight-forward structure. The Regional Director of Health (designated Leprosy Project Director) is in overall charge of the leprosy control programme which is largely funded by the NGO, in this case the Netherlands Leprosy Relief Association which provides an expatriate doctor as Project Leader. The responsible officer for the

programme is the HMG Senior Leprosy Supervisor and he is directly responsible to the Regional Director of Health as well as being his technical advisor on matters concerning leprosy. The Senior Leprosy Supervisor also runs the regional leprosy referral centre and supervises the paramedicals in the districts. These officers, usually two per district, are directly responsible to the District Public Health Officer, who is also responsible for all the Health Posts on the district.

Hence the staff at the health post are visited regularly by the district leprosy worker, occasionally by someone from the regional leprosy centre and will, from time to time, attend refresher trainings, held at the regional leprosy centre, to ensure that they can provide a reasonable service. Naturally with a larger, more experienced staff and better facilities, the regional referral centre should and does provide better quality care but will always refer patients back to the health post closest to their homes for regular treatment. There is great emphasis placed on the open access of the regional centre and peripheral staff as well as leprosy patients are encouraged to ensure that any complications are referred quickly. The firm placement of leprosy control activities in the public health services of the Nepal health structure has resulted in there being little involvement by hospitals and their staff and this anomaly has not yet been satisfactorily resolved.

DRUGS

From 12-16 October 1981 there took place in Geneva one of the most important meetings in the history of leprosy treatment. The WHO study group on the chemotherapy of leprosy, one of whose members was Dr RB Adiga of Nepal, produced their report recommending immediate adoption of multiple drug therapy.⁸ Consequently MDT implementation in Nepal began almost immediately and has been the national recommendation since then. Over the years minor modifications have been made and there are some slightly different practices in the different regions. Essentially leprosy patients with tuberculoid and borderline tuberculoid disease which is

confined to only two body areas are put onto paucibacillary MDT with double therapy for a minimum period of six months. All the rest should receive multibacillary MDT. This means that BT patients with lesions on three or more body areas, all polyneuritic cases with no skin lesions, as well as truly multibacillary patients (with borderline lepromatous and lepromatous disease) receive triple therapy for a minimum of twenty-four months of partially supervised therapy.⁷ Where then are the difficulties with drugs?

Firstly, clofazimine and rifampicin require to be taken as described in the manual. Some health workers do not understand this slightly unusual regimen and others question its scientific validity and use a regimen of their own. There is, needless to say, excellent and sound scientific justification for giving rifampicin as a once monthly pulse for a bacterium which divides no faster than once in 13 days. In addition there has now been adequate time to follow up patients released from treatment with the WHO regimens and be convinced that they are sound. The overall relapse rate of 2.6% found in the Western Region of Nepal.⁹

It compares very favourably with the 14% relapse rate among tuberculoid patients treated with dapsone monotherapy for one and a half years and 28% for all those treated with monotherapy for less than five years.¹⁰ A recent report from Gujarat showed only 0.19% of paucibacillary patients relapsing from PB MDT within three years of release from treatment.¹¹ There really is no justification for using alternative regimens from those described.¹²

Secondly, rifampicin and clofazimine are not cheap. A leprosy patient who is treated at a health post, the regional clinic or one of the mobile clinics receives his anti-leprosy drugs free. These drugs come from Ciba-Geigy in Switzerland and have been rigorously tested and are guaranteed to be potent. If the patient is being seen privately and buys from the local medicine shop, he will have to pay about NRs 9/- for his two capsules of rifampicin each month and about NRs 1400/- and NRs 100/- for

his two years clofazimine and dapsone respectively. This total of NRs 1700/- or so for a two year course of treatment is so much that most patients will be unable to continue treatment and will stop their medication prematurely.

Thirdly, as implied above, the quality of these drugs in bazaar shops is sometimes doubtful. Analysis have been recently carried out of samples of clofazimine from several small factories in India and on several counts it has been considered unsatisfactory and not recommended by the Medical Commission of the International Federation of Anti-Leprosy Associations.¹³ Tales of antibiotic capsules with less than the required weight or, even worse, impurities and inactive ingredients abound and it is obviously preferable to use medicines from a highly reputable source.

Fourthly a footnote requires to be added about the problem of dapsone hypersensitivity. Between a half and one percent of patients will be allergic to dapsone and usually within three to five weeks after starting treatment will develop symptoms referable to this.¹⁴

There are several forms in which this may present but most are accompanied by an itchy, erythematous rash all over the body. This allergic phenomenon may require simple or heroic management and some patients have died from their hypersensitivity.¹⁵ This has nearly always been due to persistent consumption of dapsone after the appearance of the first symptoms. It is essential that those who prescribe medicines have at least a rudimentary knowledge of the possible side effects of these medicines and are knowledgeable about the correct course of management required in each case.

DISEASE

Early, uncomplicated leprosy is a joy to treat. The terrifying deformities have been avoided. No stigma of the disease will remain and everybody is happy and grateful. It is estimated however that more than 30% of leprosy patients will develop some disability and by far the most common cause for this is

reaction. Reaction in leprosy is an acute immunologically mediated inflammatory phase in a leprosy patient caused by a change in the balance between the antigens of *Mycobacterium leprae* and the host's immune system. Many body organs can be targeted by reaction but the major one is the peripheral nerve trunk. It is unfortunately rarely realized that the commonest cause of peripheral neuropathy in developing countries is leprosy. Damage identified early is usually reversible and it is the persisting tragedy of leprosy that much of the misery, the deformity, the social ostracism which still exists today need never happen. Another fact which is not understood is that leprosy reaction can occur before treatment starts, during treatment and especially in the case of the short MDT regimens, after release from treatment. However, patients who are adequately informed, suitably encouraged and confident in their carers will report new reactions promptly and will often have few major sequelae.¹⁶ A third major area of confusion regards the pathogenicity of the disease and this still has profound implications within the health services and the community. Leprosy is a disease of moderately high infectivity but low pathogenicity. That simply means that in endemic areas, such as the eastern terai of Nepal where between 1 and 2 per thousand of the population are registered leprosy patients, most people have been exposed to leprosy bacilli and, at least technically speaking, have been infected. Some of them will develop a measurable immune response and there are today several research tests which can detect evidence of previous or current infection.^{17,18} Most of these, who could be called seroconverters, will never show any clinical signs of leprosy and, by WHO criteria, cannot be called cases of leprosy. It is, in all countries, a small percentage of the exposed population whose defective immune system cannot provide adequate protection, and who will develop clinical leprosy. These people have a *M. leprae* specific cellular anergy since their immune response to other antigens is normal. In most studies only 5% of spouses of a leprosy patient go on to develop the disease. Health workers, with their higher standard of living, better nutrition and awareness of hygiene

almost never develop leprosy and that particularly include those working in leprosy control work. Even if they do, it is almost invariably detected very early and treated without the appearance of complications. Therefore the anxiety, excessive precautions, reluctance to admit or treat leprosy patients is totally indefensible, particularly when the first dose of rifampicin is known to kill over 99% of all live leprosy bacilli.¹² An extension of this myth is that newly diagnosed leprosy patients require to be segregated from their children, spouses, workmates etc. A moment's reflection will reveal the illogicality of this. As with tuberculosis, there are still many unfounded prejudices based on folk lore, tradition and out dated medical ideas. If health workers still observe out dated practices, how can we expect the general population to change their beliefs?⁷ There are a further two aspects of the disease which require attention, the first being disability prevention. It must be admitted that even amongst leprosy workers it is a comparatively recent concept that plantar ulcers are not an inevitable consequence of leprosy.¹⁹ The recognition of 'at risk' eyes, hands and feet and the use of educational or simple and appropriate devices to prevent, heal and halt the progression of disabilities whether in the feet²⁰ or elsewhere¹⁶ has now become a standard component of every competent leprosy control programme. Hence all health workers who have any contact with leprosy patients should include this aspect of patient care in their management. It is, after all, the disability which accompanies leprosy which makes the disease at all noteworthy. If there was no disability, leprosy would merit no greater attention than psoriasis or acne.

The other disease-related aspect which requires attention is the problem of the management of the disabled patient. Every country where leprosy constitutes a public health problem has a policy, whether published or only tacitly understood and in most countries this has seen a gradual change over the past twenty-five years. Whereas in the past leprosy patients, and particularly the disabled, were institutionalised in large leprosaria, settlements, colonies or other euphemisms for a dumping ground, the current accepted belief is

that those people should remain with their families, in their community and contribute, to the best of their ability, to the local development. As mentioned previously, the patient on treatment, in particular on MDT, is not a source of infection and hence the practice of keeping patients at home is totally justifiable. However old beliefs change slowly and in many countries, but by no means all, there is still some degree of rejection of leprosy patients. This is sometimes confined to those with visible deformity, particularly of hands and feet. This leads to the anomalous situation where a highly bacilliferous lepromatous patient who refuses to take treatment regularly but who has not yet become disabled may be quite accepted in the community, but a burnt out case, released from treatment as bacteriologically cured, but with loss of digits or wounds will be rejected by the community and forbidden the normal social intercourse of village life. In many poor countries life is difficult for the able bodied. For those with physical disability, with little hope of family support, begging may be the only way to survive.

DOCTORS

Having covered, at some length, the drug treatment and the complications of this disease, what then is the role of the doctor in leprosy control and how can he best be equipped for his task? By the nature of the disease, the population distribution and organisation of the health services in Nepal, it will be clear that most leprosy work will be carried out in the health posts of the rural areas where the leprosy supervisor is usually a specially trained paramedical worker. Nevertheless it is common for new patients to come to a hospital for diagnosis and initial management, and if complications arise, such as drug hypersensitivity, leprosy reaction, sepsis due to anaesthesia of feet or hands, the patient may again take himself to the outpatient department of the nearest hospital. It follows therefore that doctors require to be constantly aware of the possibility of leprosy and to be adequately knowledgeable about it in order to confirm or refute the diagnosis. This means that he should be able to take an

appropriate history, test skin lesions using suitable materials to find any diminution of sensation in them, palpate the commonly affected peripheral nerve trunks and assess the three modalities of peripheral nerve function as it affects hands, feet and eyes. He requires to be able to identify leprosy reactions and in particular to judge if it is a recent problem or of long standing duration since the management for each is different. As mentioned previously, the management of anaesthesia of eyes, hands and feet, which also covers wound care and disability prevention, is essential for the patient's continued well-being. Where there is an effective and well-run leprosy control programme, it may be that it is in the patient's best interest to be referred there for further management. In some cases the leprosy clinic may operate within the hospital or from a room in the nearby District Public Health office. Qualified and experienced workers may be there to perform assessments by voluntary muscle tests and sensory tests, have health education regarding hand and foot care, be provided with specially made protective footwear or receive glasses. Often a variety of drugs are available in these clinics to treat complications. Many of the staff in rural health posts have received special training, often at one week leprosy refresher seminars, and are reasonably familiar about the management of uncomplicated leprosy. In addition, in many zones there exist special leprosy referral centres where problem cases can be referred with confidence. Of course there will be some patients who do not wish to be seen attending the local leprosy clinic. Many of the staff in rural health posts have received special training, often at one week leprosy refresher seminars, and are reasonably familiar about the management of uncomplicated leprosy. In addition, in many zones there exist special leprosy referral centres where problem cases can be referred with confidence. Of course there will be some patients who do not wish to be seen attending the local leprosy clinic. They may wish to see the doctor, either in the hospital or privately. If the doctor is adequately trained and experienced this may be a reasonable arrangement and to everyone's benefit. If not, un-necessary problems may arise. How then can we ensure that doctors in

leprosy endemic countries are adequately trained? Firstly there requires to be an appropriate input into the undergraduate curriculum, which will include practical experience in a leprosy clinic. At the same time the students require access to suitable up-to-date literature. This is the responsibility of the curriculum development authorities in each medical school and assisted, if not cajoled, by the leprosy control authorities in the region. The same, naturally, goes for all other cadres of health workers in their basic training. Thereafter there is need for refresher training and short courses should be made available to ensure that doctors are kept aware of the optimum management of leprosy patients. In Nepal it has been the practice to run annual one-week doctors courses, either in Pokhara (Green Pastures Hospital) or Kathmandu (Anandaban Hospital) and these have generally been most successful. There is also room for further education in meetings of doctors such as medical conferences, regular doctor's rounds which may be held weekly or monthly in larger hospitals or other professional meetings. The provision of specialist journals, magazines or news letters may also be of value. By utilizing all these means of ensuring better training, the quality of care provided can be raised and result in increased satisfaction to both the provider and user of the health service.

CONCLUSION

In most of Nepal the leprosy case detection rate is not falling. Assuming that case finding activities have not significantly changed, this implies that the incidence is also not falling. The only effective tool which we have to halt the transmission of the disease in the community is to identify patients, particularly the bacilliferous ones, at the earliest possible opportunity and to render them non-infectious using MDT. They then have to stay on treatment until their disease is cured. The emphasis in Nepal must therefore be on early diagnosis and the recommended drug treatment. Much research on primary prevention, by the use of anti-leprosy vaccines is under way. We would be deluding ourselves however, if we think that the answer to the

problem in the coming decade, if at all, lies with a vaccine. The vaccine trials have many more years to run. It is still unclear which groups will benefit and what vaccine to use. It is still impractical to vaccinate everyone since the vaccines are still too expensive.

It would appear that in districts where a reasonably well run leprosy control programme has been operating, the disability proportion is falling. This is the proportion of newly diagnosed patients with a WHO disability grading of greater than one in any eye, hand or foot. A falling trend suggests that patients are presenting earlier in the course of the disease and implies a satisfactory level of case finding activities. In the field programme

of the Western and Mid-western Regions, the disability proportion has fallen from 27% in 1982 to 16% in 1989. Patients who come from India to seek treatment in terai of Nepal have more disability and hence given a falsely high proportion to our figures. It can therefore be suggested that while in much of Nepal there is a reasonably good service being provided for leprosy patients, there is no immediate prospect of the problem lessening. In the increasingly urbanised terai towns much of the work load presents to the surgeries of doctors, either in the hospital out-patient department or in their private clinics. Doctors therefore have an important role in the management of this problem.

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