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CALL FOR PAPERS

Papers wanted for special issue of Leprosy Review

The Leprosy Elimination Campaigns (LECs) have been a major new initiative to detect undiagnosed leprosy patients. The first reports suggest that these campaigns have been very successful, with many thousands of new patients detected. The September 1999 issue of *Leprosy Review* will focus on LECs, reporting on their success and examining the issues they have raised. We are keen to publish as much data as possible in this issue and would like to encourage potential authors.

If you have data that you would like to publish in this Special Issue, please analyse it and write it up. Papers for this issue should be submitted to the *Leprosy Review* office by **1 June 1999 at the latest** and will go through the usual peer review process.

Diana N. J. Lockwood (Editor)

This month's poster is 'Leprosy: Differential Diagnosis No. 1: Macules', and is the first of two papers on this topic. The illustrations on the poster were generously provided by the Wellcome Trust Tropical Medicine Resource, Dr Colin McDougall and Professor Anthony Bryerson.

Future posters will include: Management of Ulcers, and Leprosy: Differential Diagnosis No. 2: Papules.

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Lepr Rev (1998) **70,** 2

Editor's Choice

In the last issue of *Leprosy Review* we were pleased to carry a first report on the 15th International Leprosy Congress in Beijing. In this issue we not only have the reports from all the workshops, but also pick up themes from the conference in both the review article and the Letters to the Editor. 'New partnerships' was a congress buzz word, emphasizing the need for the leprosy world to look outwards for new ideas and alliances. We have started to look outwards in *Leprosy Review* by reprinting a review article on disabilities (p. 3). Professor Oliver puts disabilities in a theoretical framework and illuminates wider areas of disability research that are relevant to leprosy. Oliver also echoes another conference theme when he notes that the experience of disabled people should influence research and the need to listen to their voices.

The Letters section picks up the discussion about the recent World Health Organisation recommendations on the length of treatment for multibacillary patients, with thoughtful contributions from workers in Nepal. In another letter, Keith Waddel raises the issue of intraocular lens implantation for leprosy patients. I hope that his letter will generate a response both in the columns of *Leprosy Review* and in stimulating field-based research.

Two articles illustrate the continuing need to educate people about leprosy even in endemic areas. Sadly in Southern India, 23% of teachers considered that immoral conduct caused leprosy and 63% thought that leprosy patients should be segregated. However, in Bangladesh, although there are also high levels of ignorance and prejudice, health education improved attitudes towards leprosy and in an area that had received health education 78% of respondents would buy from a shopkeeper who had leprosy.

The paper by Samant *et al.* (p. 10) shows that 13–20% of patients deteriorate after they have completed their MDT. The high levels of abnormalities in nerves in the leg and foot would not surprise Kazen, who contributes a clear article on the management of plantar ulcers (p. 63). He points out that surgery is only one part of ulcer management, far more important are the social factors, patients doing self care and joining self care groups.

I hope you will all enjoy the mix of neurology, surgery, immunology and social science in this issue.

The September issue will be themed around leprosy elimination campaigns and we are calling for papers and research on LECs for that issue. I look forward to your responses.

Diana N. J. Lockwood

0305-7518/99/070002+01

Lepr Rev (1999) **70,** 3–9

REVIEW

Theories of disability in health practice and research

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All health care and research are influenced by theories. This paper considers the influence of implicit and explicit theories[1] on interventions and research on disabled people. Another important influence is the experience of disabled people, and their increasing insistence that their voices be heard at all stages of research about their lives.[2]

The experience of disability

Over the past 20 years, writings by disabled people have transformed our understanding of the real nature of disability. They move beyond the personal limitations that impaired individuals may face, to social restrictions imposed by an unthinking society. Disability is understood as a social and political issue rather than a medical one, and this leads to critical questioning of medical interventions: attempts to cure impairments or to restore 'normal' bodily functioning. Instead, social and political solutions are sought, to challenge disabling discrimination.

Summary points

The health care that disabled people receive is influenced by theories
Positivist theory remains the dominant influence on health care given to disabled people
Other theories are beginning to have a significant influence
The rise of these theories is posing important questions for health care and research

This radically different view is called the social model of disability, or social oppression theory.[3] While respecting the value of scientifically based medical research, this approach calls for more research based on social theories of disability if research is to improve the quality of disabled people's lives. Definitions are central to understanding theories of impairment and disability.[4] In 1986 Disabled Peoples International made a clear distinction: impairment is the functional limitation within the individual caused by physical, mental or sensory impairment; disability is the loss or limitation of opportunities to take part in the

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normal life of the community on an equal level with others because of physical and social barriers.

This schema accepts that some illnesses have disabling consequences and disabled people at times are ill; it may be entirely appropriate for doctors to treat illnesses of all kinds, such as bronchitis or ulcers. Yet it questions why, for example, doctors should decide about access to welfare services such as education or disability living allowance. Theories of impairment, disability, and illness influence which aspects of disabled people's lives require health treatment, or policy developments, or political action, as sometimes radical alternatives (see box).[5]

Interventions to normalize impairments

Impairment	Intervention	Alternatives
Deafness	Cochlear implants	Sign language teaching in schools
Cerebral palsy	Conductive education	Barrier removal
Achondroplasia	Limb lengthening	Barrier removal, awareness raising
Down's syndrome	Cosmetic surgery	Awareness raising
Congenital conditions	Genetic screening	Legislation for equal opportunities

Positivism and disability research

Health research about impairment and disability is dominated by positivist theories. It focuses on searches for cures, means of reducing impairments, or assessments of clinical interventions and uses methods such as controlled trials, random statistical samples, and structured questionnaires. Even when researching disability (in the sense given above), positivist research tends to use the World Health Organisation's classification,[6] now being revised at the insistence of disabled people,[7] which is difficult if not impossible to apply in research terms and yields few useful data.

Disabled people are beginning to influence scientific research.[8] This influence poses difficulties for positivist research in questioning one of its bedrocks: the notion of objectivity. Although positivist researchers accept that subjectivity can be studied objectively, they resist involving subjects for fear of bias. However, scientific researchers often use the words 'suffering' and 'victim' as if they are accurate descriptions and not untested, biased assumptions which many disabled people do not experience. In contrast, social constructionism sees experience and subjectivity as central to the research process, and critical theory sees disabling barriers as a key research issue. Though these theories pose intellectual challenges, almost all funding goes to positivist research.

The influence of implicit and explicit positivism on the Department of Health which, it seems, has discovered the 'user' is shown in a recent report: 'The NHS is attaching increasing importance to seeking out and acting upon the views of its users on the coverage and delivery of the services it provides.'[9] The programme has spent £3·9 million on 30 projects; all are

located in universities or the health service. Despite consumer views being the second named priority for selecting research proposals, disabled people have not been involved. None of their organizations have received funding, and no projects could be said to be based on the social model of disability—they are all based on positivist theories.[10]

Social approaches within positivism

Positivist social medicine recognizes the social context to impairment as well as disability, and it examines environments as well as individuals. Hence public health measures concerned with sanitation, poverty, health education, and the like have proved extremely effective in preventing rather than curing a range of impairments such as tuberculosis, polio, rickets, and river blindness.

Prevention of impairments is complicated, however, by prenatal screening to prevent conditions such as Down's syndrome, cystic fibrosis, or Huntington's chorea, and by research into genetic engineering. Leaving aside the efficacy of such interventions, they pose profound ethical, social, and cultural issues for us all. 'Life and death decisions are vested in the hands of people who have very little understanding of the reality of disabled people's lives.'[11] With the lack of systematic evidence, why should doctors assume, for example, that life with Down's syndrome is not worth living?

Social approaches to disability[12] within positivism classify and count disabled people. Although some support this work,[13] others question the accuracy of the data[14] and say that they yield few significant changes for disabled people.[8]

Recent research, attempting to combine theories, and scientific measures of the extent of disabling barriers with disabled people's own experiences of the extent and nature of those barriers, involves disabled people in designing, collecting and analysing the data.[15] Its success remains to be seen.

Functionalist theory and disability

Influential functionalists emphasize medicine's role to cure and to maintain the 'normal' functioning of individuals and of society. In this model, the 'sick role' involves being compliant and wanting to get well.[16] This can make people with incurable conditions, including disabled people who are classified as sick, seem to be deviant. The link between disability and social deviance that functionalists make influences health care and research and supports the continued dominance of professionally controlled health and welfare services for disabled people.[17] Thus, under current welfare arrangements, more than 70% of spending goes on the salaries of professionals working with disabled people. Only recently has this been reduced through the funding of independent living schemes controlled by disabled people. A variant of functionalism, normalization theory, underlies some programmes that claim to enable devalued people to lead culturally valued lives. An example of this controversial approach is cosmetic surgery for people with Down's syndrome.

Functionalism confuses impairment and disability with the sick role. By failing to recognize that disabled people do not necessarily have 'something wrong with them' it simply reproduces discriminatory norms with values–instead of addressing the cultural and economic forces that precipitate them. The crucial problem is that disabled people, regardless

of the type or severity of their impairment, are not a homogeneous group that can be accommodated easily within a society that takes little account of their individual or collective needs. As with the whole population, disabled people differ widely in terms of ethnic background, sexual orientation, age, abilities, religious beliefs, wealth, access to work, and so on. Clearly, their situation cannot be understood or, indeed, transformed by any policy based on narrow theories of conventional normality or uniformity.

Social constructionism

This theoretical approach is centrally concerned with meaning. It shows the crucial importance of learning from disabled people's experience to understand meanings of disability. For example, blindness differs according to the economic and cultural contexts. A classic study showed that in the United States blindness was experienced as a loss requiring counselling, in Sweden as a problem requiring support services, in Britain as a technical issue requiring aids and equipment, and in Italy as the need to seek consolation or even salvation through the Catholic church.[19]

Anthropologists and historians show how different societies produce certain types of disease, impairment, and disability.[20] Disability can be produced by 'the disability business.' In modern America, industrialization, the subsequent growth of the human service sector, and the more recent politicization of 'disability rights' by the American disabled people's movement have transformed 'disability' and 'rehabilitation' into a multimillion dollar enterprise. Disability becomes a commodity and a source of income for doctors, lawyers, rehabilitation professionals, and disability activists.

These examples treat disability as a shared experience, in contrast with conventional individualistic interpretations. yet each fails to address key structural factors. Consequently, disabled people tend to be treated as an abstract, somehow distinct from the rest of the human race, and the crucial question of the causes of disability is fudged rather than clarified. For example, how is disability physically based but socially constructed by the disabling environment?[20]

Postmodernism

Postmodernism sees society in terms of fragmented and complex social structures in which social class has less importance, and other sources of social difference (including sex, ethnicity, sexuality, and disability) have more importance. Postmodernists call into question many of the certainties of earlier eras, creating multiple meanings for practically everything.

This theory has, as yet, had little impact on health research about disability. However, a study on concepts of a healthy body, so central to government health promotion, is beginning to show how these concepts can, in themselves, be disabling, unrealistic, and oppressive. 'Health promotion is working against popular culture, attempting to construct a view of health that is not privately held.[21] In other words, to have an impairment is not necessarily unhealthy; disabled people are not actually ill, and confusion between impairment and illness fails to deal with the complex meanings in the postmodern world.

Critical theory

Critical theory covers similar ground to the other theories discussed here, but sees disabled people's problems explicitly as the product of an unequal society. It ties the solutions to social action and change. Notions of disability as social oppression mean that prejudice and discrimination disable and restrict people's lives much more than impairments do.[22] So, for example, the problem with public transport is not the inability of some people to walk but that buses are not designed to take wheelchairs. Such a problem can be 'cured' by spending money, not by surgical intervention, assistive computer technology, or rehabilitation.

Ideologies perpetuate practical barriers and exclusions.[23] As long as disability is assumed to be an individual matter of personal tragedy or heroic triumph over difficulty, disabled people are excluded from society. Ordinary education, employment, buildings, public transport, and other things which most people can take for granted remain largely closed to disabled people, or at least they present obstacles which each person has to tackle individually. By emphasizing deficiency and dependency, doctors tend to reinforce these ideologies.[24]

The impact of this critical theorizing on health care and research has tended to be indirect. It has raised political awareness, helped with the collective empowerment of disabled people,[25] and publicized disabled people's critical views on health care. It has criticized the medical control exerted over many disabled people's lives, such as repeated and unnecessary visits to clinics for impairments that do not change and are not illnesses in need of treatment. Finally, it suggests a more appropriate societal framework for providing health services for disabled people.[26]

Conclusion

Implicit and explicit social theorizing, coupled with disabled people's insistence that their voices be heard, have begun to change understandings of the nature of impairment and disability. The new understandings pose key questions for health care and research if they are going to provide an appropriate knowledge base for both medical and social progress:

- What is the proper balance for investment between research into bodily impairment and into social disability?
- Who should be setting the research agenda?
- Who should be in control of the research process?
- What are the most appropriate methods for undertaking disability research?
- How should disability research be disseminated and evaluated?

Such questions help us to identify both the common ground and fundamental differences between researches.[27–29]

References

[1] Alderson P. The importance of theories in health care. *BJM*, 1998; **316:** in press.
[2] Barnes C, Mercer G, eds. *Doing disability research.* Leeds: Disability Press, 1997.
[3] Oliver M. The social model in context. In: *Understanding disability: from theory to practice.* Basingstoke: Macmillan, 1996; 30–42.

[4] Oliver M. Defining impairment and disability: issues at stake. In: Barnes C, Mercer G, eds. *Exploring the divide: illness and disability*. Leeds: Disability Press, 1996; 39–54.
[5] Shakespeare T. Re-defining the disability problem. *Critical Public Health*, 1995; **6:** 4–9.
[6] Wood P. *International classification of impairments, diseases and handicaps*. Geneva: World Health Organisation, 1980.
[7] Tennant A. Models of disability: a critical perspective. *Disability and Rehabilitation*, 1997; **19:** 478–479.
[8] Oliver M. Changing the social relations of research production. *Disability, Handicap and Society*, 1977; **7:** 101–115.
[9] Peckham M. Foreword. In: *Consumers and research in the NHS*. Leeds: Department of Health, 1995.
[10] Oliver M. Emancipatory research: realistic goal or impossible dream: In: Barnes C, Mercer G, eds. *Doing disabled research*. Leeds: Disability Press. 1997; 15–31.
[11] Begum N. Rock-a-bye baby, or the treatment might stop: a discussion of the selective treatment of disabled babies. *Critical Public Health*, 1995; **6:** 30–7.
[12] Martin J, Meltzer H, Elliot D. *OPCS Surveys of disability in Great Britain: report I—the prevalence of disability among adults*. London: HMSO, 1988.
[13] Bury M. Defining and research disability: challenges and responses. In: Barnes C, Mercer G, eds. *Exploring the divide: illness and disability*. Leeds: Disability Press, 1996; 17–38.
[14] Abberley P. Disabled by numbers. In: Levitas R, Guy W, eds. *Interpreting official statistics*. London: Routledge, 1996; 161–184.
[15] Zarb G. Researching disabling barriers. In: Barnes C, Mercer G, eds. *Doing disability research*. Leeds: Disability Press. 19977; 49–66.
[16] Parsons T. *The social system*. Glencoe, IL: Free Press, 1951.
[17] Oliver M. A sociology of disability or a disablist sociology. In: Barton I, ed. *Disability and society: emerging issues and insights*. London: Longman, 1996; 18–42.
[18] Chappell A. Towards a sociological critique of the normalization principle. *Disability, Handicap and Society*, 1992; **7:** 1.
[19] Scott RA. *The making of blind men*. London: Sage, 1969.
[20] Albrecht G. *The disability business*. London: Sage, 1992.
[21] Watson N. Health promotion and physically disabled people: implications of the national health policy. *Critical Public Health*, 1995; **6:** 38–43.
[22] Sutherland A. *Disabled we stand*. London: Souvenir Press, 1981.
[23] Abberley P. The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society*, 1987; **2:** 5–21.
[24] Oliver M. *The politics of disablement*. Basingstoke: Macmillan, 1990.
[25] Campbell J, Oliver M. *Disability politics: understanding our past, changing our future*. London: Routledge, 1996.
[26] Barnes C. *Disabled people in Britain and discrimination: a case for anti-discrimination legislation*. London: Hurst, 1991.
[27] Barnes C. Disability and the myth of the independent researcher. *Disability and Society*, 1996; **11:** 107–110.
[28] Bury M. Disability and the myth of the independent researcher: a reply. *Disability and Society*, 1996; **11:** 111–113.
[29] Shakespeare T. Rules of engagement: doing disability research. *Disability and Society*, 1996; **11:** 114–119.

Commentary

JEANETTE HYLAND

Consideration of issues raised by Oliver will benefit those of us working with people affected by leprosy. We should be aware of, think about, and relate them to our work. Oliver, Professor of Disability Studies, provides a masterly introduction to a range of theories, implicit or explicit, which currently influence approaches to disability. In considering their relevance to leprosy, we glimpse an unfamiliar perspective on a familiar phenomenon. Definition and

theory are important as they underpin planning for services.[1] Furthermore, different theories and influences shape disability research.

The main issue noted is the distinction between impairment and disability. Consider the statement: 'disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others because of physical and social barriers' (p. 1447). In the leprosy world, our present positivistic dominated outlook focuses mainly on searches for cures, means of reducing impairments (POD), assessing clinical interventions – on classification and counting of disabled persons. A broader focus is needed if we are to achieve improvement in the quality of disabled people's lives. If disability is no longer viewed solely as (defined in Oliver's parlance) 'physical impairment', then we can investigate it as a social and political issue.

New areas of awareness and study might include:

- Understanding the reality of disability in people's lives.
- Understanding the extent and nature of the physical and social barriers to people participating in normal community life.
- Examination of the causes of disability defined as social barriers to normal participation.
- Study of the nature of stigma in various cultures together with action research of stigma reduction interventions.

People affected by leprosy might themselves be included in the design, collection and analysis of data (IDEA).

Professional medical geographers, sociologists, anthropologists and others have done leprosy related work. More could be done by researchers to illuminate vistas unfamiliar to medical colleagues. However, social scientists face difficulties in gaining approval and funds for research proposals similar to those mentioned by Oliver.

Foster[2] highlighted this problem in the World Health Organisation and behavioural science research in 1982 and 1987. Proposals for leprosy research of disability using theoretical approaches and methods not familiar to medical professionals need to be judged by professional social scientists. Then we will benefit from a broader focus in our view of disability.

References

[1] Volinn, I. J. Issues of definition and their implications: AIDS and leprosy. *Soc Sci Med*, 1989; **29**: 1157–1162.
[2] Foster, G. M. Applied anthropology and international health: retrospect and prospect. *Hum Org*, 1982; **41**: 189–197.

Lepr Rev (1999) **70,** 10–20

Clinical and electrophysiological evaluation of nerve function impairment following cessation of multidrug therapy in leprosy

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Summary Seventeen multibacillary (MB) and 15 paucibacillary (PB) cases of leprosy who had had regular and adequate multidrug therapy (MDT) were examined clinically and electrophysiologically at periodic intervals for 1 year following cessation of MDT. All the major nerves were assessed for nerve function impairment (NFI). Overall, two MB (13·3%) and three PB (20%) cases showed signs of deterioration clinically and/or electrophysiologically. The nerve conduction (NC) follow-up studies revealed no significant improvement in the sensory conduction in both the MB and PB groups of nerves, whilst motor conduction showed a significant improvement at the first 6-monthly follow-up among the MB group of nerves. At the study onset, sensory impairment (MB = 62%, PB = 25%) predominated over motor in terms of both severity and frequency. The lower extremity was more frequently and severely affected than the upper in both groups of patients. As an individual test, NC measurement proved to be more sensitive in detecting NFI, but the combination of physical palpatation for nerve thickening and graded nylon test (GNT) was closely comparable to measurement of nerve conduction.

Introduction

It is well recognized that care of individuals contracting leprosy has to extend beyond antibacterial treatment as adequate treatment with MDT does not necessarily ensure clearance of bacteria or bacterial antigens.[1,2] Presence of viable bacteria and/or their antigens, particularly within the peripheral nerves, may lead to progressive involvement of peripheral nerves.[3,4] Many issues related to this persistence of bacteria and their antigens have remained inadequately addressed. Does the residual nerve damage persist for long periods or is there a gradual natural recovery? Does it progress further and cause continued impairment of nerve function? Is the post-MDT nerve involvement in paucibacillary (PB) disease any different from that in multibacillary (MB) disease?

The present longitudinal study carried out among treated leprosy patients was designed to address the above questions. A group of MB and PB leprosy cases were examined

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clinically and subjected to electrophysiological studies at periodic intervals following completion of WHO-recommended multidrug therapy (MDT) with the objective of evaluating nerve function as well as the effectiveness of MDT in arresting nerve damage.

Materials and methods

Seventeen multibacillary cases (BL/LL) treated for a minimum of 2 years and 15 paucibacillary cases (TT/BT) treated for a minimum period of 6 months with the WHO-recommended MDT regimen, i.e. rifampicin (RFP) 600 mg and 300 mg clofazimine (CLF) once a month and CLF 50 mg and diaminodiphenyl sulphone (DDS) 100 mg daily for MB and RFP 600 mg once a month and DDS 100 mg daily for PB cases of leprosy[5] were included in the study. Patient characteristics are given in Table 1.

CLINICAL EXAMINATION

All the patients were examined thoroughly by an experienced clinician to record number, size and activity of lesions and skin infiltration. All peripheral nerves were palpated to record thickness and tenderness if any. All major groups of muscles supplied by the median, ulnar, common perineal and common tibial were also tested and graded from 0 to 5 using the MRC, UK scale.[6]

SENSORY TESTING

Semi-quantitative testing for sensations was carried out using Semmes Weinstein graded nylon filaments, numbers 3·2–6·6, on fixed points on hands and feet as described by Pearson.[6] Use of graded nylon filaments has been shown to be simple, sensitive, reliable and reproducible.[7–9] The normal values for dorsal and palmer aspect of hand were ≤3·84 and for the lateral and solar aspect of foot = ≤4·9. Any values more than the above or, if doubtful,

Table 1. Study material at onset (1), first (2) and second (3) 6-month follow-up

MB (BL-LL) with minimum 24 doses of MDT-MB			PB (TT-BT) with minimum 6 doses of MDT-PB		
1	2	3	1	2	3
No. 17 Males	15	15	No. 15 Males 12 Females 3	15	15
Class: BL = 7 LL = 10			Class: BT = 13 TT = 2		
*Active = 4	Nil	1	Active = 3	Nil	Nil
*Inactive = 13	15	14	Inactive = 12	15	15
On Rx = 2	Nil	Nil	On Rx = 1	1	1
RFT = 15	15	15	RFT = 14	14	14

*Refers to skin lesional activity.
RFT = released from Rx.

an obvious difference to the contralateral side was considered abnormal. Nerve conduction studies help to evaluate the functional status of large and medium sized myelinated fibres, and a good correlation between electrophysiology and graded nylon test results is expected.

BACTERIOLOGICAL EXAMINATION

Slit skin smears were taken from six different sites to include at least one active lesion (when present), both ear lobes, and in addition any three other sites on the body. The smears were examined for the bacterial index (BI) and morphological index (MI). A lepromin test using Mitsuda lepromin was carried out on all the patients.

ELECTROPHYSIOLOGICAL STUDIES

Standard procedures were employed for recording sensory and motor action potentials for all peripheral nerves, using a Medelec MS92 EMG machine with an averager.

Sensory studies (SAP) were carried out on both left and right ulnar, median, radial, superficial peroneal and sural nerves. Sensory action potentials were recorded using surface electrodes. Motor studies (MAP) were carried out on ulnar, median, common peroneal and common tibial nerves.

Limits of normal values used for latency, amplitude and conduction velocity for sensory and motor nerves are shown in Table 2 (provided by Dr Shobha Pandya, EMG Department, Bombay Hospital). Values more than normal for latency and values less than normal limits for amplitude and conduction velocity (CV) recorded above were considered abnormal.

BIOPSIES

After the first clinical and electrophysiological recordings, a deep incision skin biopsy and a nerve biopsy were obtained from all the patients using local anaesthesia and with informed consent. Skin biopsies were taken from lesions that appeared most active, showing erythema and/or oedema. In the absence of active lesions, the choice of biopsy in the MB patients was

Table 2. Limit of normal values for sensory and motor nerves

Sensory	< Latency (ms)	> Amplitude (mv)	
Ulnar	3·5	3	
Median	3·8	7·5	
Radial	2·8	15	
Sup. peroneal	4	1	
Sural	3·8	5	
Motor	**< Latency (ms)**	**> Amplitude (mv)**	**> Conduction velocity**
Ulnar	4	5	40
Median	4	5	45
Common peroneal	6	1	39
Common tibial	6	5	37

of the ear lobes. In PB cases with no active lesions, the biopsy was taken from an inactive lesion. Selection of peripheral nerve for biopsy was done on the basis of clinical and electrophysiological evidence of involvement. While one of the sural nerves was biopsied in all the MB cases, in PB cases the selection of the nerve to be biopsied varied according to the site of involvement and included sural (6) cutaneous branch of radial (7) cutaneous branch of ulnar (1) lateral thoracic (1) and superficial peroneal (1).

Paraffin-embedded sections stained with Trichrome modified fite ferraco (TRIFF) and anti-BCG using the sandwich immunoperoxidase assay were analysed for classification of leprosy, activity of disease and extent of antigen present.

FOLLOW-UP STUDIES

Clinical, bacteriological and electrophysiological assessments were repeated twice in each case at 6-month intervals, to record signs of clinical and functional improvement or deterioration, if any.

Results

CLINICAL FINDINGS AT ONSET

Disease activity

Four of 17 MB cases and three of 15 PB cases had lesions which were clinically active, whereas all others were inactive at the time of recruitment.

Lepromin reaction

All the MB cases were lepromin negative, whereas all except one of the PB cases were lepromin positive.

NERVE THICKENING (SEE TABLE 11)

Sensory and motor impairment testing using graded nylon (GNT) and voluntary muscle testing (VMT) (see Tables 3, 4)

Among the MB cases, impaired sensory function was recorded in 90 of 170 nerves

Table 3. Results of graded nylon test in PB and MB cases at onset

	PB cases ($n = 15$)		MB cases ($n = 17$)	
Nerve	Normal	Impaired	Normal	Impaired
Ulnar	27 (90%)	3 (10%)	16 (47%)	18 (53%)
Median	28 (93%)	2 (7%)	17 (50.0%)	17 (50.0%)
Radial	26 (87%)	4 (13%)	17 (50.0%)	17 (50.0%)
Sup. peroneal	30 (100%)	0 (0%)	17 (50.0%)	17 (50.0%)
Sural	29 (97%)	1 (3%)	13 (38%)	21 (62%)
Total	140 (93%)	10 (7%)	80 (47%)	90 (53%)

Table 4. Voluntary muscle function test in 17 MB cases at onset

Nerve	Normal	Impaired
Ulnar	33	1
Median	28 (82%)	6 (18)
Common peroneal	32	2
Common tibial	32	2
Total	125 (92%)	11 (8%)

Note: only one ulnar nerve among 15 PB cases showed impaired VM function.

examined. Sural nerve involvement was most frequently recorded (21/34), followed by the ulnar (18/34). The median, radial and superficial peroneal showed involvement of comparable frequency (17/34) each. Of the 136 nerves examined for motor function (VMT) only 11 (8%) showed impairment, the median nerve being the most frequently involved (18%).

Among the PB cases 10/150 nerves showed sensory impairment. Radial nerve was more frequently involved (4), followed by the ulnar (3) median (2) and sural (1) in this order. Motor impairment was noted only in one ulnar nerve.

Electrophysiological findings on first examination (see Tables 5, 6): MB cases

Of the 170 sensory recordings and 136 motor recordings carried out in 17 MB patients, it was noted that the sensory involvement predominated over motor. In 77 (45%) of the nerves there was no sensory action potential (SAP) and another 29 (17%) showed abnormal sensory recordings (latency and amplitude). Thus, a total of 106 sensory nerves, i.e. 62% were impaired.

Among the sensory nerves, the sural nerve was the most frequently affected, followed by superficial peroneal, median, ulnar and radial in this order. However, the absence of sensory recordings was recorded most frequently in the superficial peroneal nerve. Whilst 54 (40%) nerves showed abnormal motor recordings, total absence of motor function was not detected in any of the 136 nerves examined.

Among the motor nerves, the common peroneal was the most frequently affected.

Table 5. Sensory conduction results in PB and MB cases at onset

	PB cases ($n = 15$)				MB cases ($n = 17$)			
Nerve	Normal	Impaired	Absent	Total impaired	Normal	Impaired	Absent	Total impaired
Ulnar	23	4	3	7	16	4	14	18
Median	22	6	2	8	13	12	9	21
Radial	22	5	3	8	16	9	9	18
Sup. peroneal	23	0	7	7	10	0	24	24
Sural	23	5	3	8	9	4	21	25
Total	113 (75·3%)	20 (13·3%)	17 (11·3%)	38 (25%)	64 (38%)	29 (17%)	77 (45%)	106 (62%)

Table 6. Motor conduction results in PB and MB cases at onset

	PB cases ($n = 15$)				MB cases ($n = 17$)			
Nerve	Normal	Impaired	Absent	Total impaired	Normal	Impaired	Absent	Total impaired
Ulnar	26	3	1	4	23	11	0	11
Median	26	4	0	4	24	10	0	10
Common peroneal	25	5	0	5	12	22	0	22
Common tibial	27	3	0	3	23	11	0	11
Total	104 (87%)	15 (12·4%)	1	16 (13%)	82 (60%)	54 (40%)	0	54 (40%)

Common tibial, ulnar and median showed involvement of comparable frequency. The lower extremity was more frequently and severely affected than the upper, for both sensory and motor functions.

PB cases

Of the 150 nerves tested for SAP from 15 patients, no SAP was recorded in 17. Twenty were abnormal (delayed), while the rest were within the normal limits (75%).

Of the 121 motor recordings, only one nerve showed absent motor action potential. Fifteen were abnormal and the rest were normal. As in the MB group, sensory involvement predominated over motor and the lower extremity was more commonly involved as compared to the upper. The radial, ulnar, median, sural and superficial peroneal nerves showed involvement of comparable frequency. Among the sensory nerves in the PB group also, the superficial peroneal nerve was the most severely affected (7/30 absent). Among the motor nerves, the lateral popliteal was the most commonly affected (5/31) while the median, ulnar and posterior tibial nerves showed involvement of comparable frequency.

FOLLOW-UP RESULTS

All investigations except biopsies were repeated twice at 6-month interval. Only those patients, with complete follow-up data were considered for the final analysis.

CLINICAL FINDINGS

MB cases

Fifteen MB cases were available for the final analysis, of whom 11 had unchanged GNT and VMT, two showed marginal sensory improvement and two showed sensory/motor deterioration.

Of the four MB cases whose patches were recorded as clinically active at onset, three became clinically inactive at the second 6-month follow-up, i.e. after 1 year. The fourth patient was recorded as inactive at the first 6-month follow-up, but showed active skin infiltration along with deterioration in GNT charting at the second 6-month follow-up.

PB cases

Of the 15 PB cases, nine showed no change, three improved and three deteriorated neurologically.

The deterioration among the three PB cases was in the form of development of an active skin lesion, recurrent ulnar and median neuritis with appearance of a new skin lesion and recurrent abscess formation in one of the ulnar nerves. The patient with a new skin lesion was lost for follow-up, while the one with recurrent neuritis continued to show progressive deterioration despite a full course of MDT-MB, after having taken a course of MDT-PB. The patient with ulnar nerve abscess had absent sensory conduction in the nerve from the first NC examination.

Three of 15 BT cases where patches were recorded as active at onset became inactive at the second follow-up, one of them having received 9 months of MDT-PB.

Bacteriological follow-up findings

In all except two patients, there was a significant decline in the smear BI during the follow-up investigations. In two cases the smear BI remained static around 3+.

All the PB cases were smear negative at onset and they remained negative during the follow-up.

Electrophysiological follow-up (sensory and motor) findings (see Tables 7, 8, 9 and 10)

In order to determine whether there was any significant overall improvement or deterioration in either sensory or motor conduction recordings during the two 6-month follow-ups, the total numbers of normal recordings at three intervals were compared. The biopsied nerves were

Table 7. Sensory conduction follow-up – MB

	Normal	Impaired	Absent	Total impaired
Initial	54 (40%)	29 (22%)	52 (39%)	81 (60%)
Second	60 (44%)	23 (17%)	52 (39%)	75 (56%)
Final	62 (46%)	24 (17%)	49 (36%)	73 (54%)

No significant differences were observed.

Table 8. Motor conduction follow-up – MB

	Normal	Impaired	Absent	Total impaired
Initial	76 (63%)	43 (36%)	1	44 (37%)
Second	102 (85%)	12 (14%)	1	13 (15%)
Final	105 (88%)	14 (12%)	1	15 (12%)

A highly significant critical ratio = 3·9611 ($p = 0{\cdot}01$) was observed between the initial and second visits.

Table 9. Sensory conduction follow-up – PB

	Normal	Impaired	Absent	Total impaired
Initial	109 (79%)	18 (13%)	11 (8%)	29 (21%)
Second	98 (83%)	10 (8%)	10 (8%)	20 (17%)
Final	116 (84%)	11 (8%)	11 (8%)	22 (16%)

No significant differences were observed.

Table 10. Motor conduction follow-up – PB

	Normal	Impaired	Absent	Total impaired
Initial	91%	8%	1%	9%
Second	94%	3%	3%	6%
Final	93%	4%	3%	7%

No significant differences were observed.

excluded in this analysis. The total number of normal sensory recordings at the onset, first and second follow-up or between onset and second follow-up showed no statistically significant differences in both the MB and PB group of nerves. It was therefore concluded that there was no statistically significant improvement in the sensory conduction velocity in both MB and PB patients studied. However, the motor recordings showed a significant improvement at the first 6-month follow-up [critical ratio (CR) = 3·9611, $p = 0{\cdot}01$] and remained steady at the second 6-month follow-up among the MB group of nerves. No significant improvement was noted in the motor recordings among the PB nerves.

Clinicoelectrophysiological correlation at onset (see Table 11)

Among the MB group of patients, of the 238 nerves tested at the study onset 82 (34·5%) were recorded as thickened on physical palpation, 94 (39·5%) nerves were recorded as abnormal using graded nylon whereas 139 (58·4%) nerves were recorded as abnormal using electrophysiology. Among the PB group of patients, of the 210 nerves tested 27 (12·9%) were palpably thick, 10 (4·8%) showed graded nylon abnormality and 45 (21·4%) of the nerves were abnormal electrophysiologically. Thus electrophysiological recordings revealed a significantly higher number of involved nerves as compared to either physical palpation or the graded nylon test in MB as well as the PB group.

Discussion

In the present study, a group of 15 each of multibacillary (BL/LL) and paucibacillary (TT/BT) cases of leprosy were assessed for change in nerve functions for a period of 1 year following cessation of MDT. Two MB (13·3%) and three PB (20%) cases showed signs of deterioration in nerve function clinically and/or electrophysiologically.

Table 11. Clinicoelectrophysiological correlation at onset

	MB Group			PB group		
Nerves examined	Thickened	GNT & VMT	NC Ab.	Thickened	GNT & VMT	NC Ab.
Ulnar	20	18	18	6	3	7
Median	0	17	21	3	2	8
Radial	10	17	18	5	4	8
Sub. peroneal	20	17	24	5	0	7
Sural	7	21	25	3	1	7
Common tibial	17	2	11	1	0	3
Common peroneal	8	2	22	4	0	5
Total (%)	82	94	139	27	10	45
% Abnormal	(34·5%)	(39·5%)	(58·4%)	(12·5%)	(4·8%)	(21·4%)

CR = 5·2386(HS)
CR = 4·1261(HS)
CR = 5·0625(HS)
CR = 2·3305(MS)

Ab. = abnormal; GNT = graded nylon test; NC = nerve conduction study; VMT = voluntary muscle testing; CR = critical ratio; HS = highly significant: ($p < 0·01$); MS = marginally significant: ($p = 0·05$).

The electrophysiological follow-up studies in MB and PB cases of leprosy during the first year of cessation of MDT showed no significant improvement in the sensory conduction in both MB and PB group of nerves. However, the motor conduction showed significant improvement, though only among the MB group of patients at the first 6-month follow-up. It remained static at the second follow-up. This was not surprising, as the motor conduction was least affected at the onset and unlike PB nerves, there were a large number of nerves (40%) that had shown mild involvement. The reversal of delay in motor conduction in these nerves could be attributed to subsidence of inflammation and oedema and/or reduction in bacterial antigens and immune complexes.

The bacterial load declines in the skin at a steady rate following cessation of MDT.[5] A similar trend was noted in the present study. However, such longitudinal data are not available for the peripheral nerves. Random studies carried out on nerves show prolonged persistence of bacteria and antigens even in patients who were consistently smear negative.[1–3] Thus subsidence of oedema and inflammation is the most likely mechanism for the improvements found in motor conduction velocity.

As mentioned in the methodology, nerve biopsies obtained at the onset from this group of patients were studied using both light and electron microscope. The results are documented elsewhere.[10] The regenerating/remyelinating myelinated fibres were seen in large numbers in several of the nerves studied. However, this is not a hallmark feature of treated nerves, as regenerating/remyelinating fibres were often seen in actively involved nerves of untreated cases of leprosy.[11] A majority of the nerves that were biopsied were grossly involved sural nerves showing no recordable sensory action potential. Also, a majority of the nerves showing absent sensory action potential at the onset remained so throughout the follow-up. It can be extrapolated, therefore, that the regenerating/remyelinating activity noted in the biopsied nerves was not functionally reflected in the NC and/or clinical recordings. One of the explanations could be that the remyelination was incomplete or discontinuous, or there was collateral sprouting. In both situations, an inordinate delay in the propagation of action

potentials would result in absent sensory action potentials. None of the tests used in the present study was sensitive enough to gauge the extent of remyelination or further worsening in these nerves.

Special mention must be made of the two MB cases who had shown deterioration in nerve function during the follow-up. One MB case showed simultaneous sensory deterioration and a new active skin lesion at the second follow-up. The patient was restarted on MDT-MB for 1 year; the response was good and the skin lesion subsided. The second MB patient, who deteriorated to develop glove and stocking type of anaesthesia, remained so at the subsequent clinical follow-up.

As expected, the sensory involvement predominated over motor, both in terms of severity and frequency. The lower extremity was more severely and frequently involved than the upper in both MB and PB cases of leprosy. Among the sensory nerves in the MB group, the sural nerve was found to be the most frequently involved (73·5%), followed by the superficial peroneal nerve (70·5%). The latter was also found to be the most severely affected nerve (all absent recordings). The median (62%), ulnar (53%) and radial nerves (53%) were next in order. Among the motor nerves, the common peroneal was the most frequently affected nerve (65%). The common tibial, ulnar and the median nerves showed involvement of comparable frequency (50% each).

There was a good concordance between clinical and electrophysiological abnormalities noted in the nerves examined, in that all the clinically involved nerves (80/150 = 47%) showed electrophysiological involvement. Besides, 22/150 (14%) sensory nerves and 15/120 (12·5%) motor nerves that were clinically normal showed NC abnormality, proving NC to be more sensitive in detecting sensory and motor impairment. Biopsy of few such nerves obtained in this study confirmed histologically demonstrable lesions in these nerves.

Significantly in the present study, a combination of physical palpation and use of graded nylon could collectively detect involvement of 32·8% of nerves, only marginally less than that detected by nerve conduction studies (41·1%). It demonstrates that under field conditions, combination of the above two tests could serve as the most useful tool for detecting the nerve function impairment. Electrophysiology should be recommended only under special circumstances for further confirmation or as a research tool.

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References

[1] Shetty VP, Suchitra K, Uplekar MW, Antia NH. Higher incidence of viable *Mycobacterium leprae* within the nerve as compared to skin among multibacillary leprosy patients released from multidrug therapy. *Lepr Rev*, 1997; **68:** 131–138.

[2] Shetty VP, Suchitra K, Uplekar MW, Antia NH. Persistence of *Mycobacterium leprae* in the peripheral nerve as compared to skin of multidrug treated leprosy patients. *Lepr Rev*, 1992; **63:** 329–336.
[3] Shetty VP, Uplekar MW, Antia NH. Immunohistological localization of mycobacterial antigens within the peripheral nerves of treated leprosy patients and their significance to nerve damage in leprosy. *Acta Neuropathol*, 1994; **88:** 300–306.
[4] Van Brakel WH, Khawas IB. Silent neuropathy in leprosy: an epidemiological description. *Lepr Rev*, 1994; **65:** 350–360.
[5] WHO. Study group on chemotherapy of leprosy for control programmes. World Health Organisation, 1982: TRS 675.
[6] Pearson JMH. The evaluation of nerve damage in leprosy. *Lepr Rev*, 1982; **53:** 119–130.
[7] Antia NH, Mehta LN, Shetty VP, Irani PF. Clinical, electrophysiological, quantitative, histologic and ultrastructural studies of the index branch of the radial cutaneous nerve in leprosy. I. Preliminary report. *Int J Lepr*, 1975; **43:** 106–113.
[8] Mehta LN, Shetty VP, Antia NH, Irani PF. Quantitative, histologic and ultrastructural studies of the index branch of the radial cutaneous nerve in leprosy and its correlation with electrophysiologic study. *Int J Lepr*, 1975; **43:** 256–264.
[9] Bell-Krotoski JA. 'Pocket' filaments and specifications for the Semmes–Weinstein monofilaments. *J Hand Ther*, 1990; **Jan–Mar:** 26–31.
[10] Jacobs JM, Shetty VP, Antia NH. A morphological study of nerve biopsies from cases of multibacillary and paucibacillary leprosy given multidrug therapy. *Acta Neuropathol*, 1993; **85:** 533–541.
[11] Shetty VP, Antia NH, Jacobs JM. The pathology of early leprous neuropathy. *J Neurol Sci*, 1988; **88:** 115–131.

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Childhood leprosy in an endemic area

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Summary A study was done on 794 new cases of leprosy among children (aged 0–14 years) detected and treated with MDT during 1990–1995 in Gudiyatham Taluk, South India. Incidence rates of leprosy and proportion of multibacillary cases increased with age, while bacillary + tuberculoid was most common. Over 80% had a single patch and most children were detected through surveys. Nearly 30% had history of household contacts with leprosy, mostly parents or grandparents. Reactions and relapses were not uncommon. The findings emphasize the need for more careful surveys for case detection and better follow-up in case management.

Introduction

Several aspects of transmission and epidemiology of leprosy are still unclear or remain controversial.[1–6] Studies on leprosy among children could unravel some of these questions, especially if the manifestations and process of discovery are carefully observed. Reports on childhood leprosy are based on cross-sectional prevalence surveys of institutionalized or general populations.[7–9] Transmission within households based on contact surveys has also been reported.[1–9] The advent of multidrug therapy (MDT) gave hope of a rapid decline in leprosy, especially among children. The fact that such hopes were not realized even after 15 years, especially in areas of good coverage and monitoring of the control programme, has raised concern and the need for more intensive studies.

A study on childhood leprosy was undertaken to record changes in the presentation of the disease 10 years after the introduction of MDT in Gudiyatham Taluk. The profile of these children at detection and their follow-up in terms of relapses and complications are presented and discussed in this paper.

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Materials and methods

The study was done in Gudiyatham Taluk on an area highly endemic for leprosy, situated in North Arcot Ambedkar District of Tamil Nadu, India. It had a population of 385,228 in 1961, swelling to about 576,146 in 1991. A leprosy control unit of the Schieffelin Leprosy Research and Training Centre (SLR & TC) was established in 1962. A population survey of the area carried out in 1966 showed an overall prevalence rate of 29/1000; the lepromatous index for children below 14 years in the 1966 survey was 3·7.[10] Periodically, this population was screened for new cases through general surveys, contact surveys and school surveys. Voluntary reporting was encouraged through health education of the community. Cases detected by paramedical workers or non-medical supervisors were confirmed by medical officers. Smears were taken from four different sites: right ear, left forehead, right chin and left buttock or thigh. Suspect patients who did not have the cardinal signs of leprosy were kept under observation for a period of 3 months and reviewed, and/or a skin biopsy taken.

Patients were classified according to the criteria of Ridley and Jopline,[11] and were reclassified into paucibacillary (PB) multibacillary (MB) as suggested by the World Health Organisation.[12] When the aggregate of skin and truncal nerve lesions reached 10 in a patient, the MBR-MDT (multibacillary regimen) was prescribed. Anyone showing a positive skin smear irrespective of the clinical classification was treated in the same way. Detailed case records were kept and stored in a computer data bank.

All children who were less than 15 years of age at their last birthday when registered during 1990–95 were included. They were divided into three age groups: group 1, children below 5 years of age; group 2, children between 5 and 9 years of age and group 3, those between 10 and 14 years of age.

Results

A total of 2540 leprosy patients were registered during 1990–95. Of these, 794 (31·3%) were children, whose ages and sex are shown in Table 1.

There were 36 children in group 1, 290 in group 2 and 468 in group 3. Except among the under-fives, there was a slight preponderance of males within M : F ratio being 1·25 : 1.

INCIDENCE

Age–sex specific incidence rates of leprosy were computed using the estimated population in

Table 1. Childhood leprosy cases detected during 1990–95 by age and sex

	Age (years)					
Sex	(Gr. 1) 0–4	(Gr. 2) 5–9	(Gr. 3) 10–14	All children 0–14	Adults 15 and over	Total
Male	16	61	248	425	885	1310
Female	20	129	220	369	861	1230
Total	36	290	468	794	1746	2540

Table 2. Estimated annual incidence rates (per 10,000)* among children by age and sex

Sex	Age (years) (Gr. 1) 0–4	(Gr. 2) 5–9	(Gr. 3) 10–14	All children 0–14	Adults 15 and over	Total
Male	0·75	8·17	11·90	6·86	7·13	7·04
Female	0·99	6·94	11·10	6·31	7·46	7·07
Total	0·87	7·57	11·51	6·59	7·29	7·06

*Based on age–sex distribution of estimated population in Gudiyatham Taluk, 1993.

the various age groups based on the National Census of Gudiyatham Taluk. The findings are given in Table 2.

The incidence rates (per 10,000) increased steadily from 0·87 in group 1 to 7·57 in group 2 and 11·51 in group 3.

TYPE OF LEPROSY

The different types of leprosy affecting the children are presented in Table 3.

Only 16 (2%) were classified as MB, of which only one was a pure lepromatous leprosy (LL) (0·1%). None in group 1, 4 (1·4%) in group 2 and 12 (2·5%) in group 3 had MB leprosy. Sixteen children had positive skin smears taken from routine or selective sites. Borderline tuberculoid (BT) was the commonest type encountered in the children in all three groups.

MODE OF DETECTION

Surveys remained the main mode of detection of leprosy in children. School surveys resulted in 328 (41·3%) patients, general survey in 212 (26·7%) and survey of contacts in 73 (9·2%).

Table 3. Childhood leprosy by age and classification

Classification	Age (years) (Gr. 1) 0–4 No.	%	(Gr. 2) 5–9 No.	%	(Gr. 3) 10–14 No.	%	(All) 0–14 No.	%
PN	—	—	—	—	2	0.4	2	0.3
IND	2	5.5	31	10.6	47	10.0	80	10.1
TT	13	36.1	84	29.0	118	25.2	215	27.1
BT	21	58.3	171	59.0	289	61.8	481	60.5
BL	—	—	4	1.4	11	2.3	15	1.9
LL	—	—	—	—	1	0.2	1	0.1
Total	36	100.0	290	100.0	468	100.0	794	100.0

PN = pure neutral, IND = indeterminate, TT = tuberculoid, BT = borderline tuberculoid, BL = borderline lepromatous, LL = lepromatous leprosy.

Table 4. Age and duration of the disease (in years)

Duration of leprosy (years)	Age (years) (Gr. 1) 0–4	(Gr. 2) 5–9	(Gr. 3) 10–14	(All) 0–14 No.	%
≤ 1	35	268	400	703	88·5
2–3	1	16	46	63	8·0
4–5	–	4	14	18	2·3
> 5	–	2	8	10	1·3
Total	36	290	468	794	100·0

Only 181 (22·8%) children were voluntarily brought forward. The classification of leprosy and site of lesion did not vary significantly according to mode of detection.

HOUSEHOLD CONTACT

Family members of a leprosy patient living together under the same roof and partaking of meals from a common kitchen were called household contacts. Overall, 237 (29·8%) gave a history of contact within the household. Forty-four percent of the children in group 1 had a member of the family with leprosy. In groups 2 and 3, the positive history of contact was elicited in a smaller proportion of children—just 29·5%. The index case was a parent in 40% of those giving a history of household contact, a grandparent in 14%, a sibling in 18% and a distant relative for others. Fifteen children were exposed to multiple cases in the household. The ratio of MB/PB among household contacts developing leprosy was not different from that of others; six of 16 MB were from household contacts, two from multiple case families.

DURATION OF DISEASE

The duration of disease as stated by the parents is presented in Table 4.

The duration of disease was mostly under a year, except in the older age groups. It is surprising that there are missed cases with duration more than 3 years.

NUMBER OF PATCHES

Nearly 83% of the children had a single patch, as displayed in Table 5.

Two, three and four to five patches occurred in 8, 2 and 2% of the children, respectively. Multiple patches occurred in 5%.

DISTRIBUTION OF PATCHES

The distribution of the patches was on the exposed parts of the body, in order of magnitude, hand, face, leg and knee, in 546 (68·7%) children, while 242 (30·5%) children had patches on the covered parts of the body, thigh, trunk and buttock.

Table 5. Age and patches

	Age (years)				
	(Gr. 1)	(Gr. 2)	(Gr. 3)	(All) 0–14	
Patches	0–4	5–9	10–14	No.	%
0	–	–	5	5	0·6
1	28	240	392	660	83·1
2	3	23	34	60	7·6
3	1	9	7	17	2·1
4–5	2	7	5	14	1·8
> 5	2	11	25	38	4·8
Total	36	290	486	794	100·0

FOLLOW-UP

Based on records, data on follow-up were studied up to the end of 1996. Seventeen children left the study area, 11 after released from treatment (RFT) after paucibacillary regimen (PBR) and four during (PBR) treatment. Two smear positive cases also left during the course of treatment.

RELAPSES

Despite their completing 6 months of PBR prescribed according to body weight, relapses occurred in 13 children with PB leprosy. Three occurred during the 2-year surveillance period after completion of treatment, and another five, two and three occurred 6, 12 and 18 months after surveillance. Old skin lesions became clinically active in five and increased in size in three, new skin patches appeared in two and recurrence of foot drop in three was noted at RFC or during surveillance. A further 6 months of PBR-MDT (paucibacillary regimen) was given to seven children. Treatment with MBR/MDT was started in the other six children. In three, foot drop had recurred; one of them relapsed with a positive repeat skin smear. Multiple new patches had appeared in one child and clinical assessment and skin biopsy confirmed the presence of active disease in another. One child, a girl, who had 11 patches and negative skin smears when first detected, left the area after receiving 16 pulses of MBR-MDT. She returned to the study area 3 years later with positive skin smears. She was restarted on MBR-MDT.

REACTIONS

Among MB patients one child had six to seven episodes of erythema nodosum leprosum (ENL) reaction apart from one episode of reversal reaction. Two children had two episodes of reversal reaction each and one child had one episode of reversal reaction. All responded well to steroids. Twenty-nine children with paucibacillary disease had reversal reactions or/and neuritis. An episode of reversal reaction in skin was noted in 14 children at detection, in eight during MDT, in another eight during surveillance and in nine after releasing from control. Only five of these patients had reversal reaction in skin alone. Neuritis was observed in 13 children at detection, in seven during surveillance and in eight after release from control. Nerve abscess occurred in three cases during treatment, and in four during surveillance; all of them received a WHO recommended course of steroids. Clawing was observed in four cases,

which included two children with purely neuritic leprosy (PNL) and two children with borderline tuberculoid who had severe motor weakness with repeated neuritis. This did not improve with steroids and PB regimen and hence required surgery.

SELF HEALING

Seven cases were assumed to have self healed, as they were inactive at the time of detection till the end of 1996.

Discussion

Comparison of current data with that of surveys done earlier in the same geographic area reveals that while the incidence of leprosy in children has remained static, the proportion of multibacillary cases has declined significantly.[10,13] The lepromatous index (LI) declined from 3·7 in 1966 to 0·13. Whether this is due to observer variations, effect of MDT or other operational factors or changing epidemiology of the disease needs further investigation.

Incidence rates among members of leprosy affected families living under the same roof have been shown to be higher than those in the general population;[14,15] such rates have increased further with multiple cases in the family. While this is reflected in the present study, it is a matter of concern that more than 50% of young children have reported no household contact. This requires a wider definition of household contacts to include neighbourhood contacts as well as more detailed questioning on possible source of infection. Such cases have a challenging role for intensive epidemiological investigations using modern laboratory technology, on possible environmental and nutritional factors that are likely to compromise the immunity of the children.

The study revealed maximum incidence rates among children aged 10–14 years. Given a long incubation period, it can be inferred that younger children are indeed at the greatest risk. Often such children showing any typical sign are ignored as if they cannot harbour the bacteria.[16] The more recent evidence that indeterminate leprosy is a precursor of lepromatous leprosy[17] does indeed emphasize the need for greater caution in ruling out leprosy among young children, and strengthens the need for less invasive diagnostic tests.

The study confirms that most children have only a single lesion, and reveals the difficulties in classifying children with a single large patch over the wrist or forearm. A few of these children have had repeated reversal reactions and deformities as a consequence. Could they have done better on an MB regimen and the early use of steroids? Children with multibacillary disease are also at higher risk for reversal reactions. They require regular follow-up and prompt use of steroids for the prevention of deformity. At the present time, there is no system for the follow-up of children with multibacillary disease who migrate out of the area. This leaves the possibility of their transmitting the disease to others.

More efficient surveys in detecting cases of leprosy as early as possible among both younger and older children are urgently needed.[18] The present methods are not only inefficient but inadequate. Girls usually drop out of school earlier than boys and are missed during routine school surveys. Intensive sample surveys using modern laboratory techniques would be valuable in studies of childhood leprosy to unravel some of the mysteries in transmission of the disease.[19] Follow-up strategies for early detection of neuritis are also imperative to prevent nerve damage at such an early age.

Adequate leprosy control requires not just availability of MDT, but other essential arrangements for early case finding, diagnosis of relapse, detection of reactional states, etc. Much credit has been given to MDT for the dramatic reduction in prevalence of leprosy worldwide,[20] but this is mainly due to shortening of the duration of treatment and the register-clearing that has accompanied its introduction. It is changes in incidence rather than prevalence that provide evidence that the transmission of disease is being interrupted.[21,22] The present study does not support the conclusion that leprosy is fading out and emphasizes the need to monitor the magnitude and profile of childhood leprosy in order to understand better its epidemiology and control.

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References

[1] Rao PSS, Karat ABA, Kaliaperumal VG, Karat S. Transmission of leprosy within households. *Int J Lepr*, 1975; **43**: 45–54.
[2] Kirchheimer WF. Animal models for research in leprosy. *Lepr Ind*, 1973; **45**: 6–11.
[3] Rees RJW, McDougall AC. Airborne infection with *Mycobacterium leprae* in mice. *J Med Micro*, 1977; **10**: 63–68.
[4] Ridley JC. The presence of *M. leprae* in human milk. *Lepr Rev*, 1967; **38**: 239–242.
[5] Porritt RJ, Olsen RS. Two simultaneous cases of leprosy developing in tattoos. *Am J Pathol*, 1947; **23**: 805–817.
[6] Narayanan E, Manja KS, Bedi BMS, Kirchheimer WF, Balasubrahmanyan M. Arthropod feeding experiments in lepromatous leprosy. *Lepr Rev*, 1972; **43**: 188–193.
[7] Nadkarni NJ, Grugni A, Kini MS, Balakrishnan M. Childhood leprosy in Bombay: a clinico-epidemiological study. *Ind J Lepr*, 1988; **60**: 173–188.
[8] Ganapati R, Naik SS, Acharekar MY, Pade SS. Leprosy endemicity in Bombay: an assessment through surveys of municipal schools. *Lepr Rev*, 1976; **47**: 127–131.
[9] Dave DS, Agarwal SK. Prevalence of leprosy in children of leprosy parents. *Ind J Lepr*, 1984; **56**: 615–621.
[10] Karat ABA, Sadananda G Rao, Karat S, Job CK. Epidemiological studies in leprosy in Gudiyatham Taluk. Part 1. *Lepr Rev*, 1967; **38**: 77–82.
[11] Ridley DS, Jopling WH. Classification of biopsy according to immunity. A five group system. *Int J Lepr*, 1966; **34**: 255–273.
[12] World Health Organization. Report of a study group chemotherapy of leprosy for control programmes. *WHO Tech Rep Series*, 1982; **675**: 21–26.
[13] Rao PSS, Karat ABA, Kaliaperumal VG, Karat S. Prevalence of leprosy in Gudiyatham Taluk, South India – Part 1. Specific rates with reference to age, sex and type. *Int J Lepr*, 1972; **40**: 157–163.
[14] Jesudasan K, Bradley D, Smith PB, Christian M. Incidence rates of leprosy among household contacts of primary cases. *Lepr Ind*, 1984; **56**: 600–614.
[15] Rao PSS, Jesudasan K, Mani K, Christian M. Impact of MDT on incidence rates of leprosy among household contacts. Part 1. Baseline data. *Int J Lepr*, 1989; **57**: 647–651.
[16] Brubaker ML, Meyers WM, Bourland J. Leprosy in children one year of age and under. *Int J Lepr*, 1985; **53**: 517–523.
[17] Job CK, Baskaran B, Joseph J, Aschhoff M. Histopathologic evidence to show that indeterminate leprosy may be a primary lesion of the disease. *Int J Lep*, 1997; **65**: 443–449.
[18] Fine PEM. Leprosy: the epidemiology of a slow bacterium. *Epidemiol Rev*, 1982; **4**: 161–170.
[19] Dayal R, Bharadwaj VP. Prevention and early detection of leprosy in children. *J Trop Paed*, 1995; **41**: 132–138.
[20] Noordeen SK. Elimination of leprosy as a public health problem. *Lepr Rev*, 1992; **63**: 1–4.
[21] WHO study group. *Epidemiology of leprosy in relation to control TRS 716*. WHO, Geneva, 1985.
[22] Jakeman P, Smith WCS. Evaluation of multidrug therapy programme of leprosy control. *Lepr Rev*, 1994; **65**: 289–296.

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Is knowledge of leprosy adequate among teachers? A comparative study

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Summary A cross-sectional comparative study on the levels of knowledge and attitude on leprosy among teachers and students was carried out in a rural area of Vellore district in Tamil Nadu, India. A total of 30 teachers and 120 students participated in the study. It was found that knowledge about leprosy among teachers was inadequate. Only 23·4% of teachers stated that germs caused leprosy, while 23·4% mentioned immoral conduct, 20·0% marrying a leprosy patient, 6·6% insects and 26·6% did not know the causes of leprosy. While 80·0% of teachers knew that anaesthetic hypopigmented patches were a sign of leprosy, enlarged painful nerves were not mentioned by a single teacher, although this sign was identified by 17·5% of students. Teachers had a more positive attitude towards leprosy than students and this was statistically significant ($p < 0·001$). This paper discusses the need for continuous education, especially for teachers and through them the students, using different media so as to ensure sustained knowledge for behavioural change in the community.

Introduction

A lack of accurate knowledge about leprosy in the community may be an important factor in hindering leprosy control. Health education has been described as a central component of anti-leprosy activities which are promoted in many countries where the disease is endemic.[1]

Studies have assessed the knowledge and attitude of leprosy patients,[2–4] the community,[4–7] nurses[8] and doctors.[7,9–11] A number of studies[12–14] have documented the effectiveness of health education given on leprosy to school students. Mutatkar[15] in his review stated that knowledge attitude practice studies indicated a lack of accurate knowledge about leprosy among the general population as well as patients.

In 1975, Gershon *et al.*[16] studied the impact of health education programmes on the awareness and attitude of teachers regarding leprosy in Madras, Southern India. In 1976, Mutatkar[7] selected teachers as one of the nine categories of people he had studied in both

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experimental and control areas of Poona and Jalgaon, in assessing the effectiveness of the health education programme of the National Leprosy Eradication Programme (NLEP) by the Gandhi Memorial Leprosy Foundation. Since then, there have been no studies on the knowledge levels of teachers. This indicates the lack of priority that health workers have given to this core group of teachers.

Another study[17] was carried out in 1985 by RUHSA Department among teachers in a neighbouring area. A large proportion of the teachers were unaware of the cause, symptoms and communicability of leprosy, and prevention of deformity. This study compares the level of knowledge and attitude about leprosy among teachers and students.

Materials and methods

The study design was a cross-sectional knowledge, attitude and behaviour (KAB) survey of school teachers and students in K.V. Kuppam Block, Vellore District, Tamil Nadu, India. This is one of the three blocks in Gudiyatham Taluk, which is the leprosy control area of the Schieffelin Leprosy Research and Training Centre (SLR&TC) at Karigiri, Vellore District. The prevalence of leprosy in the control area declined from 25·8 per 1000 in 1970 to 14·2 per 1000 in 1981.[18] It has decreased further to 11·44 per 1000 in 1986 and to 1·95 per 1000 in 1993.[19]

Out of nine high schools and two higher secondary schools in the block four high schools and one higher secondary school were randomly selected. From each school, 24 students were selected using systematic random sampling. There were 12 girls and 12 boys from each of the three mixed schools and 24 boys and 24 girls from each of the two single sex schools, respectively. Six teachers were randomly selected from each school. The total sample in this study consisted of 120 students and 30 teachers.

The variables studied were knowledge about cause, symptoms, spread, consequences, treatment and prevention of leprosy. Information on attitude and behaviour of students and teachers towards leprosy was also obtained. The perception of ideal treatment and actual practice was also studied.

The data were collected by one trained data collector using a pretested interview schedule. Quality control measures included cross-checking of 5% samples, spot checks and editing 100% of the schedules. The data were analysed manually using percentages and chi-squares as the statistical measures.

Results

Interesting results were obtained from the comparison of knowledge, attitude and behaviour regarding leprosy between the students and teachers. The stark contrast can be seen in Table 1. Among students, 57·4% knew that germs cause leprosy, while only 23·4% teachers identified this correctly. This difference is statistically significant ($p < 0·001$). Among teachers, 23·4% and 20·0%, respectively, identified insects and marrying a leprosy patient as causes. Finally, 26·6% of teachers had no idea of the cause of leprosy. The teachers' knowledge of the cause of leprosy was poorer than that of the students.

Most of the teachers (80%) knew that anaesthetic hypopigmented patches were one of the symptoms of leprosy, while only 43% of students recognized this (Table 2). A variety of

Table 1. Knowledge on cause of leprosy

Cause of leprosy	Students		Teachers	
	No.	% $n = 120$	No.	% $n = 30$
Germs	69	57·4	7	23·4
Insects	17	14·2	2	6·6
Immoral conduct	17	14·2	7	23·4
Marrying a leprosy patient	–	–	6	20·0
No idea	17	14·2	8	26·6
Total	120	100·0	30	100·0

symptoms, including loss of sensation in the hands and legs, enlarged painful nerves, enlarged ear lobes with loss of eyebrows and shining skin, were mentioned by the students. This is significantly more than what the teachers stated ($p < 0·001$). It is notable that none of the teachers cited enlarged painful nerves as one of the symptoms, whilst 17·5% of the students mentioned this.

Regarding consequences, both groups identified the different consequences (Table 3). However, a notable finding was that 13·3% of the teachers indicated that there were no changes as a result of leprosy. Unlike the teachers, a significant proportion ($p < 0·001$) of the students knew that ulcers in hands and feet and chronic illness were consequences of leprosy.

The students attempted to answer questions on the mode of spread, with a number of them giving acceptable answers, e.g. physical contact (24·2%), staying in the infected patient's house (25·9%), sneezing (46·0%), cough (44·0%) and soil (7·5%). Unexpectedly, most of the teachers did not answer. Surprisingly, four teachers indicated that leprosy is spread by bad conduct.

Among the teachers, 66·7% were able to say that leprosy is not hereditary. A surprise finding was that 23·3% of the teachers stated that it was hereditary and 10% were totally ignorant. Among students, 56·6% were ignorant.

All the teachers except one stated that leprosy was curable. Nearly 85% of the students also knew that it was curable. The source of treatment was correctly stated by 73·3% of the teachers and 45% of the students. The teachers were generally aware that the allopathic system was the best for treatment. The students were not sure of treatment, but the majority recommended allopathy.

Table 2. Knowledge on signs and symptoms of leprosy

Signs & symptoms	Students		Teachers	
	No.	% $n = 120$	No.	% $n = 30$
Anaesthetic hypopigmented patches in the body	51	42·5	24	80·0
Loss of sensation of hands and legs	41	34·2	6	20·0
Enlarged painful nerves	21	17·5	–	–
Enlarged ear lobes with loss of eyebrows and shiny skin	13	10·8	1	3·3

Table 3. Knowledge on consequences of leprosy

Consequences	Students		Teachers	
	No.	% $n = 120$	No.	% $n = 30$
Deformities	58	48·3	17	56·7
Ulcers in hands and feet	26	21·7	2	6·7
Chronic illness	38	31·7	3	10·0
Anaesthetic patches throughout the body	4	3·3	–	–
No change	–	–	4	13·3

While knowledge on preventing deformities was relatively high among both teachers and students, over one-third of the students were ignorant in this area. Only 50% of students, but 90% of teachers, knew that deformities can also be treated. Teachers had a significantly ($p < 0·001$) positive attitude towards leprosy patients compared to students (Table 4).

Cross-tabulation did not show any significant association between level of knowledge on leprosy and age, caste, father's and mother's education, years of education and years of experience as a teacher. However, there was a significant association ($p < 0·05$) between housing type (type of roof) and level of knowledge, with those students living in terraced and tiled houses having more knowledge than those living in thatched houses.

Discussion

Reviewing the literature, it was surprising to identify only two studies which measured teachers' knowledge of leprosy. In contrast, a number of studies were available on knowledge of leprosy among the target groups, such as students, parents and the general community. Mutatkar[7] rightly pointed out in the 1970s that teachers are an organized and powerful group in the community. They have a profound influence on their students. Teachers could have a significant role in teaching basic facts about leprosy, assisting diagnosis by identifying suspicious patches early, and helping to prevent victimization of leprosy-affected children.

The WHO[20] Expert Committee has repeatedly recommended the training of various groups of personnel, including teachers, as health educators in leprosy. They are likely to

Table 4. Attitude towards leprosy

Attitude	Students Positive Response		Teachers Positive Response	
	No.	% $n = 120$	No.	% $n = 30$
Should leprosy patients be segregated from the community?	41	34·2	19	63·3
Would you allow a leprosy patient to sit next to you?	27	22·5	18	60·0
Would you eat in the house of a leprosy patient?	18	15·0	16	53·3
Would you allow a leprosy patient to touch you?	26	21·7	17	56·7

increase the health consciousness of the students. WHO has also recommended that attention be directed at Teacher Training Centres.

In the Mutatkar[7] study, the education programme consisted of two lectures and one slide show for the teachers of Poona, the experimental group. Even the study[16] on teachers carried out in Tamil Nadu measured their knowledge after only 3 h of a single session of teaching on leprosy. Although there were statistical differences between the teachers of Poona and Jalgaon, there was too little change, even in Poona, for a true comparison. Only 9·2% of teachers in Poona after education knew that leprosy was caused by germs, as opposed to 4·3% in Jalgaon. In the Gershon[6] study, of those stating germs as the cause, an increase from 7·1% to 68% was observed among teachers between pre- and post-evaluation. In the present study, 23·4% of teachers and 57·4% of students were aware of germs as a cause of leprosy. Further, 40·8% teachers in Poona, and 51·8% in Jalgaon stated that leprosy is hereditary, whereas in the Gershon study it was 23·5% before education and nil after education. In the present study, 23·3% teachers stated that it was hereditary.

Bhore *et al.*[12] have found that child-to-parent education may show promising results in leprosy education in developing countries. In this setting, most parents of school children are illiterate and are not easily reached by conventional methods of health education. Jacob's[13] study also confirms this. Another study carried out by Prem Kumar *et al.*[14] did not show a significant transfer of knowledge through students to their parents. The authors themselves accepted the limitation of a small sample size and no instructions being given to the children to pass on the message. There was only one education session. However, it was observed in another study from Tamil Nadu[21] that when teachers and students were systematically taught any health education message, they were able to transfer their knowledge to their parents.

In the earlier studies[12,16] quoted, it has been observed that after obtaining the pre-programme level of knowledge of students, health educators were used to teach the students on leprosy. On the other hand, if they had taught the teachers, the educational process could have been sustained over a much longer period.

The NLEP of India has found a low correlation between knowledge and attitude among the community with relation to leprosy.[22] The study by Raju and Koparty[5] in Andhra Pradesh and Orissa States in India showed that in Andhra, 50% of the respondents had a high knowledge level; however, only 25% had a positive attitude towards leprosy, indicating that good knowledge and a positive attitude do not necessarily go together. However, in Orissa almost all respondents had a negative attitude towards leprosy. In the present study, even though the teachers had low levels of knowledge, they had high positive attitudes.

Teachers can play a vital role in leprosy education, as the majority of the community passes through the school system. Teachers' knowledge and attitude should be sound enough to bring about a behavioural change among the students. It is necessary to carry out similar studies on teachers in other parts of the state and country, relating not only to leprosy but other diseases such as tuberculosis, cancer and AIDS. If the findings are similar, then serious efforts must be made to educate teachers about the commonly prevalent diseases. If teachers, the key educators in any country, are ignorant about diseases like leprosy, then we cannot expect rapid changes in early diagnosis and treatment. It has been proved that when teachers are correctly educated, they can effectively transfer this knowledge through the school children to their parents.[21]

In conclusion, it can be stated that while health service providers, including health educators and social workers, can bring about behaviour changes in target groups, only teachers can bring about this change in the community as a whole through the school

children. However, to bring about this change, teachers need to be trained over a period of time, using different media so that they can retain the knowledge gained and pass on the messages relating to leprosy and other diseases to students in an ongoing sustainable manner.

References

[1] Mehendale MS. Health Education in leprosy. In: *A manual of leprosy*, Thangaraj RH (ed.). The Leprosy Mission, New Delhi, 1987, Chapter 22, 372–394.

[2] Raj V, Garg BR, Lal S. Knowledge about leprosy among leprosy patients. *Lepr India*, 1981; **53:** 226–230.

[3] Kumar RK, Ramaniah TBBSR, Jessie FSNKB, Sabhesan S. Level of knowledge of leprosy patients towards their ailment. *Lepr India*, 1983; **55:** 107–110.

[4] Myint T, Thet AT, Htoon MT, Win M. A comparative KAP study of leprosy patients and members of the community in Hlaing and Laung-Lon Townships. *Ind J Lepr*, 1992; **64:** 313–322.

[5] Raju MS, Kopparty SNM. Impact of knowledge of leprosy on the attitude towards leprosy patients: a community study. *Ind J Lepr* 1995; **67:** 259–271.

[6] Tekle-Haimont R, Forsgren L, Gebre-Mariam A *et al*. Attitudes of rural people in Central Ethiopia towards leprosy and a brief comparison with observation on epilepsy. *Lepr Rev*, 1992; **63:** 157–168.

[7] Mutatkar RK. *Society and leprosy*. Gandhi Memorial Leprosy Foundation, Sharad Gogate Publishers, 1979: 29, 35, 37.

[8] Awofeso N. Appraisal of the knowledge and attitude of Nigerian nurses toward leprosy. *Lepr Rev*, 1992; **63:** 169–172.

[9] Uplekar MW, Cash RA. The private GP and leprosy: a study. *Lepr Rev*, 1991; **62:** 410–419.

[10] Ramanathan U, Ramu G. Attitude of doctors to working in leprosy. *Lepr India*, 1982; **54:** 695–699.

[11] Sandhu HS. Knowledge, attitude and practice of leprosy among doctors in Bhopal. *Ind J Lepr*, 1984; **56:** 633–640.

[12] Bhore PD, Bhore CP, Powar S *et al*. Child to parent education. A pilot study. *Ind J Lepr*, 1992; **64:** 51–57.

[13] Jacob MS, Amar D, Christopher A, Keystone JS. Transmission of health information on leprosy from children to their families in an urban centre. *Lepr Rev*, 1994; **63:** 272–278.

[14] Prem Kumar R, Keystone JS, Christian M, Jesudason K. Transmission of health information on leprosy from children to their families: another approach to health education. *Lepr Rev*, 1991; **62:** 58–64.

[15] Mutatkar RK. Social science research on leprosy: a review. In: *Social science research and social action for leprosy control*, Srinivasan H (ed.). Indian Association of Leprologists, 1991: 98.

[16] Gershon W, Mani RS, Roopkumar KSB. Programme for Health Education among school teachers. A study conducted at GREMALTES. *Lepr India*, 1981; **53:** 641–655.

[17] Sivasankaran S. *Field study report on knowledge and perception of school teachers on leprosy*. RUHSA Central Library D-03, FSR-15, 1985–86: 1–41.

[18] Christian M, Rao PSS, Pannikar VK. Epidemiology of leprosy in Gudiyatham Taluk. *Ind J Lepr*, 1984; **56:** 687–688.

[19] Jesudasan K, Rao PSS, Jayaraj T, Raja Samuel JD. Changes in prevalence of leprosy in different clinic areas of Gudiyatham Taluk 1970–1993. *Ind J Lepr*, 1994; **66:** 359.

[20] WHO. *Fourth report of expert committee on leprosy*. Tech Rep Services, 1970: 459.

[21] Saminathan P, Ravindranath MJ, Abel R. Health Messages for adults—from their children. *World Health Forum*, 1986; **7:** 191–193.

[22] Mutatkar RK, Ranade MG. Evaluation of Health Education in leprosy control programme: methodological considerations. *SE Asia J Trop Med Public Health*, 1986; **77:** 437–441.

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Knowledge, attitude and practice regarding leprosy and tuberculosis in Bangladesh

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Summary A small survey was carried out in two areas of northern Bangladesh to assess and compare the level of knowledge, attitude and practice towards leprosy and tuberculosis (TB) among two communities that differed widely in the amount of health education received about these diseases. The results indicate that without a health education programme, levels of knowledge about the cause and treatability of the diseases are poor, worse for leprosy than TB, with correspondingly negative attitudes. Only 16% of the respondents in the 'uninformed' area mentioned 'skin patch' in a question about what they knew about leprosy; and only 44% mentioned 'cough' as a symptom of TB. In the area that had received health education, 90% mentioned, respectively, 'skin patch' and 'cough'. Seventy-eight percent of the respondents would not buy goods from a shopkeeper known to have leprosy, 76% if he had TB in the uninformed area; but in the community who had received health education the proportions were reversed, with three-quarters agreeing to purchase from a diseased shopkeeper. The implications of these findings for the DBLM and National Health Education programmes are discussed.

Introduction

Leprosy and tuberculosis (TB) are considered to be major public health problems in Bangladesh, and both are the subject of very active control programmes in which the Government of Bangladesh (GoB) and Non-Government Organisations (NGOs) are sharing resources to achieve the aim of disease control. Both the GoB and NGOs are involved in health education campaigns to the population. Since 1993, the GoB Leprosy and TB Control Services have been involved in IEC (Information, Education and Communication) activities with the general public through radio, TV, newspaper advertising, advocacy meetings, handbills, stickers and posters. The aim has been to present succinctly the signs and symptoms of TB and leprosy, and the availability of treatment at health posts and clinics. Leprosy and TB NGOs assist the GoB in certain specified districts in the country, under a Memorandum of Understanding signed in 1994. These NGOs have developed their own

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materials and methods of health education, including use of radio, slide shows, cinema slides, posters, stickers, handbills, drama and puppet shows. Again, the content has focussed on the signs and symptoms of disease and availability of treatment.

However, the authors could find no publications relating to the knowledge, attitudes and practice of the community towards leprosy and TB in Bangladesh, or of the effectiveness of mass health education. It is the authors' experience that prejudice against leprosy and TB sufferers is quite high in the country, and that there is much ignorance about the cause and treatability of these two diseases. Anecdotal evidence from colleagues working in different locations supports this view. Since Bangladesh is geographically close and culturally quite similar to India, a review of some of the studies carried out there may be relevant, as well as further afield.

In a large study carried out in 1995 in two Indian states, Raju and Kopparty[1] found moderately high levels of knowledge about leprosy but surprisingly negative attitudes. About 50% of respondents from Andhra Pradesh had a 'high' knowledge level, 35% in Orissa. However, almost all the subjects from Orissa (569/599, 95%) had a negative attitude towards leprosy, and 75% from Andhra Pradesh. In Mangalore, southern India, only 15% of community members knew the early signs of leprosy, and 60% felt it was necessary to segregate patients.[2] This study was carried out in 1985. In another survey in 1975 in Chingleput, Ramu and others found that 84% of community members thought that leprosy was caused by the 'malefic influence of stars', and none of their respondents was prepared to marry into a family with leprosy in it.[3] In another study carried out in Myanmar (Burma), knowledge about leprosy was generally poor, with significant levels of stigma present in the community.[4] Even in the United States, considerable stigma has been found to exist. Gussow and Tracy, in a survey carried out in 1972, found that 60% of non-professional workers in the department of Public Health in California thought that leprosy sufferers should be isolated, and 68% thought it was not acceptable for leprosy sufferers to work around other people.[5]

Publications describing community knowledge, attitudes and practices relating to TB are very few indeed, and the authors could find none relating to the Indian subcontinent. However, the available literature suggests that it shares some characteristics with leprosy. Ebner (1968) asked respondents in Baton Rouge, Louisiana, near the leprosy centre at Carville, 'what diseases stand out in your mind as being the worst or least desirable?'. The answers showed that syphilis, mental illness, TB and leprosy were at the top of the list.[6] Barker, in analysis of a sociological study, concluded that 'the popular concept of leprosy is almost identical with that of tuberculosis'.[7] In Birmingham, England, Bakhshi and Ali found that 94% of TB patients did not suspect TB when the symptoms first appeared, and that knowledge about the signs and symptoms of the disease was lower among the non-white, largely Asian, community.[8]

Danish Bangladesh Leprosy Mission (DBLM) is a large NGO administered by The Leprosy Mission operating in four districts of northern Bangladesh for the control of leprosy and TB in partnership with the Government. We decided to conduct a small Knowledge, Attitude and Practice (KAP) study to try and understand better what the opinions of the rural community are, and to compare the knowledge, attitudes and practices on leprosy and TB among two areas, one which had received regular and intensive health education, and one which had not.

Materials and methods

The study was carried out by the Danish Bangladesh Leprosy Mission (DBLM) in north-west

Bangladesh in September 1997. DBLM is responsible to the Government of Bangladesh for administering a leprosy and TB control programme covering the two north-western districts of Thakurgaon and Panchagar. The leprosy project started in 1978 and covers an area known to have the highest prevalence of leprosy in the country (up to 5/1000 in NW Bangladesh).[9] The leprosy case detection rate in 1996 was 4·1 per 10,000. The TB control programme started in 1994.[10] The incidence of new sputum smear positive tuberculosis (TB) is estimated to be 1·1/1000,[11] and in 1996 the TB case detection rate was 4·0 per 10,000. The population according to the 1991 Census is 1,798,600 and the area covered is 3213 km^2.

STUDY AREAS

Two rural areas in Panchagar district were selected for the survey. Both areas are broadly similar, being populated by a majority Muslim community of small landowners and landless day labourers, with a few more major landowners. One of the areas, Pamoly Union, has had extensive health education coverage by DBLM staff over a period of 2–3 years. By contrast, the other area, Boroshoshi Union, has had hardly any health education coverage by DBLM staff, since it is geographically difficult to access. The Unions each have a population of about 20,000.

THE SURVEY

A questionnaire was developed with the aim of assessing knowledge, attitudes and practice towards leprosy and TB. Two local Bangladeshis, one male and one female, one Muslim and one Hindu, were selected to carry out the survey. One was a DBLM Physiotechnician, the other a woman who had worked as a DBLM Leprosy Control Assistant. Neither of these workers had worked in the study area at any time. After fully discussing the questionnaire with them to ensure they clearly understood it, the two workers conducted a pilot study with the questionnaire. After feedback, the form was modified and a final version prepared for the survey. The questionnaire was kept deliberately short, since it is difficult to get the attention of busy householders for much longer than an hour.

Within each Union, a village was selected, and the interviewers chose a house near the centre of each village to start from. They then worked serially, going from house to house until 50 households had been covered in each village, giving a total of 100 interviews. The interviewers simply stated that they wanted to find out what the families thought about leprosy and TB, without explaining that they worked for DBLM, or 'Danish' as it is locally known. Instead of interviewing individuals, the interviewers requested that all the members of the household there at the time should be present for the interview. Most of the time the head of the household took a lead in responding to the interviewer, frequently consulting with other family members. We felt this was a reasonable approach, since in Bangladesh illnesses are rarely private and a sufferer would be expected to ask the views of other members of his or her household.

The survey was carried out over 2 separate weeks in September 1997. Each survey took 5 days in each Union to complete, doing 10 interviews of 40–50 min per day. After the survey, the questionnaires were analysed and the results entered into a simple database written using Epi-Info software.

HEALTH EDUCATION PROGRAMME

The Health Education programmes on the signs and symptoms of TB and availability of treatment had been conducted regularly in Pamoly Union over 2 years. These included a day/night mass information programme run from a jeep using flip charts, a bullhorn loudspeaker and two locally developed slide series showing simple stories about leprosy and TB sufferers who receive successful treatment. The slide series had been shown five times in evening sessions over the 2 years, with an audience of several hundred each time. In addition, in 1995 all schools were visited and information given about both diseases. The local DBLM TB/Leprosy Control Assistant (TLCA) had also been active in conducting contact surveys and group health education activities in shops and bazaars. By contrast, Boroshoshi Union had received only one mass day/night information programme during the same period. The local TLCA responsible for Boroshoshi Union has visited the area minimally, for geographical reasons.

STATISTICAL METHODS

Results were analysed using the Chi squared (χ^2) test to indicate the strength of the evidence against the null hypothesis in Epi Info software ver. 6.01. Independent sample *t*-tests for the comparisons of means were carried out using SPSS for Windows, ver. 6.1.

Results

THE TWO SELECTED AREAS

In Boroshoshi Union, there was a mean of 3·3 people living in each household, and 2·6 in Pamoly (difference significant, $p < 0{\cdot}05$). The mean area of land owned by the households was higher in Pamoly (2·1 hectares) than Boroshoshi (0·7 hectares; $p = 0{\cdot}064$, *t*-test) with a correspondingly significantly higher monthly income of Tala 2450 (US$61) versus Taka 1550 (US$39) ($p < 0{\cdot}05$, *t*-test). The skew was mainly due to a small number of rich landowners in Pamoly (eight with >4 hectares). The proportion of landless households did not differ significantly (Pamoly 38%, Boroshoshi 28%, $p = 0{\cdot}39$), in fact with a higher number in the correspondingly 'richer' Pamoly. The religious makeup of the two communities did not differ significantly, with 78% Muslim in Boroshoshi and 74% Muslim in Pamoly, the remainder being Hindu ($p = 0{\cdot}64$).

KNOWLEDGE ABOUT LEPROSY AND TB

Knowledge levels about both diseases were low in the 'unreached' community in Boroshoshi. Interestingly, knowledge about leprosy appears to be even lower than about TB—the question *What do you know about leprosy?* shows very few mentioned key words such as 'patch' (16%), 'sensation loss' (0), or even 'deformity' (6%), with 62% returning a 'don't know'. By contrast, to the question *What do you know about TB?*, 44% replied 'cough' for TB and 48%, blood in the sputum. Knowledge about where the diseases come from was similarly poor for both, with 96% returning 'don't know' for leprosy and 80% for TB. Sixty-four percent thought that ordinary people could get leprosy, and 46% thought leprosy was curable, 58% for TB. However, in Pamoly, where there has been a high level of community education,

knowledge about both diseases was significantly higher. The key words 'patch' and 'sensation loss' were mentioned by 90% and 50%, respectively, with respect to leprosy, and 'cough' and 'blood in sputum' by 90% and 94% with respect to TB. Knowledge that both diseases were curable was very high (leprosy, 94%; TB 95%), as was the knowledge that treatment was freely available (leprosy, 96%; TB, 78%). However, the majority were still unclear about the cause of leprosy (don't know, 84%) and TB (don't know, 64%); a very low proportion cited 'germs' as a cause of leprosy (4%) and TB (2%). There was a misconception about smoking and TB, with about a fifth of the respondents reporting smoking as a cause of TB.

All of the statistical differences between Pamoly and Boroshoshi and TB are significant with a p value of $<0{\cdot}05$ (χ^2 test).

ATTITUDES TOWARDS LEPROSY AND TB

Table 1 shows that there are alarmingly high levels of stigma attached to both diseases, with prejudice towards TB level being on a par with leprosy. In all, 74–76% of families would not allow a leprosy or TB sufferer to eat with the family, and would not buy goods from a shopkeeper who was a sufferer. Anecdotally, several families reacted with anger when the suggestion was made that they might buy goods from a diseased shopkeeper. Around 50% of families would not share a tubewell with a neighbour if his son had TB or leprosy, and a very high 94% of families stated that they would not permit their son to marry a girl with cured leprosy, 88% for a girl with cured TB.

Once again, a markedly lower level of prejudice was demonstrated in the community in Pamoly, with between 18% and 28% of households giving negative, prejudicial answers to the four questions.

PRACTICE ABOUT LEPROSY AND TB

Table 2 shows a reliance on private qualified 'MBBS' doctors and village doctors (informally trained allopathic practitioners) rather than leprosy and TB clinics in the unreached Boroshoshi community, significantly reversed in Pamoly. Similarly, knowledge about DBLM, its provision of free service and knowledge of its clinic location was very low in Boroshoshi (88–92% 'don't know' to these three questions), while 72% of respondents had heard about DBLM in Pamoly.

Discussion

This small study shows high levels of ignorance and prejudice towards leprosy and TB, both of which are endemic in Bangladesh and the current focus of control strategies. We had thought that impoverishment was the principal social consequence of infection by TB.[10,12] However, this survey shows that levels of knowledge about TB, while higher than for leprosy, are still inadequate; and that levels of prejudice are of about the same level, as was found in the USA.[6,7] These findings are in line with the community studies carried out in India and Myanmar mentioned in the Introduction, which also found low levels of knowledge about leprosy in the community and high levels of expressed prejudice towards sufferers. While it

Table 1. Attitudes towards TB and leprosy

Leprosy related questions	Answer	Responses: Boroshoshi *n* (%)	Responses: Pamoly *n* (%)	TB related questions	Answer	Responses: Boroshoshi *n* (%)	Responses: Pamoly *n* (%)
Can a leprosy sufferer eat with his or her family?	Yes	9 (18)	35 (70)	Can a TB sufferer eat with his or her family?	Yes	10 (20)	38 (74)
	No	38 (76)	15 (30)		No	27 (74)	12 (24)
	Don't know	3 (6)	0 (0)		Don't know	3 (6)	0 (0)
		$\chi^2 = 28{\cdot}34$, $p < 0{\cdot}05$, degrees of freedom = 2				$\chi^2 = 24{\cdot}49$, $p < 0{\cdot}05$, degrees of freedom = 2	
If a shopkeeper had leprosy, would you buy from his shop?	Yes	12 (24)	39 (78)	If a shopkeeper had TB, would you buy from his shop?	Yes	11 (22)	38 (76)
	No	38 (76)	11 (22)		No	37 (74)	12 (24)
	Don't know	0 (0)	0 (0)		Don't know	2 (4)	0 (0)
		$\chi^2 = 29{\cdot}27$, $p < 0{\cdot}05$, degrees of freedom = 2				$\chi^2 = 29{\cdot}63$, $p < 0{\cdot}05$, degrees of freedom = 2	
Would you let your neighbour use your tubewell if his son had leprosy?	Yes	22 (44)	41 (82)	Would you let your neighbour use your tubewell if his son had TB?	Yes	25 (50)	39 (78)
	No	27 (54)	9 (18)		No	23 (46)	11 (22)
	Don't know	1 (2)	0 (0)		Don't know	2 (4)	0 (0)
		$\chi^2 = 15{\cdot}73$, $p < 0{\cdot}05$, degrees of freedom = 2				$\chi^2 = 9{\cdot}30$, $p < 0{\cdot}05$, degrees of freedom = 2	
Would you let your son marry a girl with cured leprosy?	Yes	3 (6)	36 (72)	Would you let your son marry a girl with cured TB?	Don't know	4 (8)	0 (0)
	No	47 (94)	14 (28)		Yes	4 (8)	36 (72)
					No	44 (88)	14 (28)
		$\chi^2 = 45{\cdot}78$, $p < 0{\cdot}05$,				$\chi^2 = 45{\cdot}10$, $p < 0{\cdot}05$, degrees of freedom = 2	

Table 2. Practice about leprosy and TB

Leprosy related question	Answer	Responses: Boroshoshi *n* (%)	Responses: Pamoly *n* (%)	TB related question	Answer	Responses: Boroshoshi *n* (%)	Responses: Pamoly *n* (%)
What would you do if you thought you might have leprosy	Lep. Clinic	9 (18)	30 (60)	What would you do if you thought you might have TB?	TB. Clinic	11 (22)	37 (74)
	Private Dr.[a]	17 (34)	9 (18)		Private Dr.[a]	20 (40)	11 (22)
	Village Dr.[b]	12 (26)	1 (2)		Village Dr.[b]	15 (30)	0 (0)
	Trad. Healer[c]	6 (12)	10 (20)		Trad. Healer[c]	0 (0)	0 (0)
	Don't know	6 (12)	0 (0)		Don't know	4 (8)	2 (4)
		$\chi^2 = 30{\cdot}08$, $p < 0{\cdot}05$, degrees of freedom = 4				$\chi^2 = 32{\cdot}36$, $p < 0{\cdot}05$, degrees of freedom = 4	

[a]Private registered 'MB BS' doctor.
[b]Village doctor: informally trained village medical practitioner.
[c]Traditional healer.

may be true that north Bangladesh is particularly poor in terms of knowledge and attitudes towards these two diseases, the rest of the country is unlikely to be very different.

Reassuringly, it appears that the area with the well-conducted community health education campaign showed a higher level of knowledge and more favourable attitudes. At least in Bangladesh, this should be a message of importance to both the GoB and NGOs as they plan their strategy for control of these two diseases. Since both diseases have an important social dimension, it is crucial that the community understands the cause and treatability of these two infections, both so that possible cases can present to a diagnostic facility without hindrance, and so that people receiving treatment can continue to live and be fully integrated into the community. It shows that health education *can* make a large difference to community attitudes towards these two diseases, thus significantly reducing the suffering associated with them. It must be easier to have leprosy or TB in Pamoly than in Boroshoshi.

However, there were indications that attitudes still lag behind knowledge, as has been found elsewhere.[1] About a quarter of respondents in the area that had received health education still believed that leprosy or TB sufferers should not eat with the family members, although the majority (> 90%) knew that both diseases were curable. A similar proportion would not buy from a diseased shopkeeper, share a tubewell or marry into a family with leprosy or TB. Changing prejudicial attitudes on any subject is an enormous challenge in any culture. It is probably true that the 'final change' will not come about until it is clear by personal, local community observation that both diseases, once treated, present no risk to the community. Jopling in his review on leprosy stigma[13] stresses that the availability of MDT is the key to reduction in stigma. Therefore, making it easy and possible for sufferers to receive early and effective treatment is a necessary adjunct to any campaign of health education.

As a project, DBLM felt that in general this study provided confirmation that its health education programme was proceeding in the right direction, while recognizing that there are 'black holes' where the programme has, for one reason or another, not been sufficiently intense to bring about a reversal of knowledge and attitudes, as in Boroshoshi. These areas need identification and targeting. DBLM has an active health education committee composed of senior staff involved in field work and disability prevention, whose brief is to continue to develop ways of bringing the message that 'leprosy and TB are curable' to the community.

This is a small study, also limited because the two communities differed significantly in income and land ownership, while being comparable in religious makeup. The study design (a descriptive cross-sectional study), strictly speaking, did not enable us directly to assess the effectiveness of the campaign, since for this objective it would have been necessary to assess knowledge, attitudes and practices in the same area before and after the implementation of a health education programme. Boroshoshi Union is geographically isolated, and for this reason received little health education about leprosy and TB from DBLM. It may be that its relative social isolation within the locality is part of the explanation of why knowledge about the diseases was so poor, and attitudes so negative. It would be very valuable to follow up this study with another, identical survey carried out on the same families in Boroshoshi in a year or two's time, after the area has been targeted for health education.

However, the study does suggest that a well-executed campaign of health education can dramatically change levels of knowledge about leprosy and TB, and reverse prejudicial attitudes.

In summary, this study shows high levels of knowledge and more favourable attitudes towards leprosy and TB in an area that had received intensive health education. In contrast,

there were very low levels of knowledge and unfavourable attitudes in a comparable area that had not had health education activities.

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References

[1] Raju MS, Kopparty SNM. Impact of knowledge on the attitude towards leprosy patients: a community study. *Ind J Lepr*, 1995; **67:** 259–272.
[2] Shetty JN, Shivaswamy SS, Shirwadkar PS. Knowledge, attitude and practices of the community and patients regarding leprosy in Mangalore—a study. *Ind J Lepr* 1985; **57:** 613–619.
[3] Ramu G, Dwivedi MP, Iyer CGS. Social reaction to leprosy in a rural population in Chingleput district (Tamil Nadu). *Lepr India*, 1975; **47:** 156–169.
[4] Myint T, Thet AT, Htoon MT, Win M. A comparative KAP study of leprosy patients and members of the community in Hlaing and Laung-Lon townships. *Ind J Lepr*, 1992; **64:** 313–324.
[5] Gussow Z, Tracy GS. The phenomenon of leprosy stigma in the continental United States. *Lepr Rev*, 1972; **43**: 85–93.
[6] Ebner JD. *Community knowledge and attitudes about leprosy: a social–psychological study of the degree of stigmatisation of a chronic disease.* MA thesis, Department of Sociology, Louisiana State University, Baton Rouge (quoted in Gussow and Tracy[5]).
[7] Barker DS. Concepts of disabilities. *Personnel and Guidance Journal*, 1964; **43:** 371 (quoted in Gussow and Tracy[5]).
[8] Bakshi SS, Ali S. Knowledge, attitude and behaviour of TB patients. *J Public Health Med*, 1995; **17:** 343–348.
[9] Richardus JH, Croft RP. Estimating the size of the leprosy problem: the Bangladesh experience. *Lepr Rev*, 1995; **66:** 158–164.
[10] Croft RA, Croft RP. Tuberculosis control is good for established leprosy programmes. *Lepr Rev*, 1996; **68:** 139–146.
[11] Weyer K. *Tuberculosis in Bangladesh, 1996.* Report prepared for the Bangladesh TB Review, November 1997 (unpublished).
[12] Croft RA, Croft RP. Expenditure and loss of income by tuberculosis patients before reaching effective treatment in Bangladesh. *Int J Tuberc Lung Dis*, 1998; **2:** 252–254.
[13] Jopling WH. Leprosy stigma (Editorial). *Lepr Rev*, 1991; **62:** 1–12.

Lepr Rev (1999) **70,** 43–46

Viability and drug sensitivity of *M. Leprae* isolated from long-term WHO/MDT treated multibacillary leprosy patients

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Introduction

The ALERT Leprosy Control Programme introduced WHO/MDT in Ethiopia in January 1983. Paucibacillary patients are treated for 6 months with self-administered daily dapsone and rifampicin once monthly under supervision. Multibacillary patients are treated for a period of at least 2 years or until the skin smears become negative. Treatment consists of self-administered dapsone, clofazimine and rifampicin and clofazimine monthly under supervision.

In 1990, the ALERT leprosy control and the ALERT Hospital Services observed multibacillary patients who were suspected to be unresponsive to the WHO/MDT regimen. The basis of this concern was that by the yearly skin slit examination, the bacteriological index (BI) did not decrease by 1 log unit per year, despite adequate compliance and above 80% attendance rate, with the WHO-recommended MDT. Using the mouse foot pad assay system, we tested for viable bacilli from some of these patients from 1992 to 1993.

Materials and methods

Forty-one patients, who were still on chemotherapy, were enrolled in the study. The patients were subjected to a 4–6 mm punch biopsy and their tissue biopsy was processed for mouse foot pad inoculations. Depending upon the bacterial yield, up to 10^4 acid-fast bacteria (AFB) from each biopsy were inoculated to each mouse foot pad whenever possible. In the absence of identifiable bacilli, 30 μl of the suspension was inoculated to each pad of BALBIC mice and harvested a year later.

'Multiplication' means that the number of AFB harvested pad was $\geq 10^5$ AFB per foot pad. Thus viability of bacilli is based upon viable bacteria to multiply.

When growth was observed, mouse-to-mouse passages were carried out for sensitivity studies to dapsone, clofazimine and rifampicin. Therapy was stopped in these patients at the beginning of 1994, and future follow-up to assess clinical status and bacteriological status was planned.

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Table 1. Viability of *M. leprae* isolated from MB leprosy patients with poor BI reduction on long-term treatment with WHO/MDT (1992–1993)

				Passage and sensitivity to		
				DDS (%)	GLOF (%)	RIF (%)
Average RX in years	No. of patients	Average BI at testing	Viability test results	00·0001, 0·001, 0·01	0, 0·0001, 0·001, 0·01	0·003, 0·03
2–3 years	17	1. 4·5	0/8 Total 5/17	Passage was not possible due to small quantity of bacterial available for inoculation.		
		2. 4·8	0/8			
		3. 4	0/8			
		4. 4·7	0/8			
		5. 3·8	0/6			
		6. 5	4/4			
		7. 2·7	4/4			
		8. 3	1/7			
		9. 1·4	2/8			
		10. 4·7	1/8			
		11. 3·4	0/8			
		12. 1·4	0/5			
		13. 4	0/8			
		14. 2·5	0/8			
		15. 1·5	0/8			
		16. 4·7	0/8			
		17. 3·5	0/8			
> 3 < 5 years	15	1. 3·4	0/6 Total 3/15	2/2 Sensitive		
		2. 1·2	0/7			
		3. 1·2	0/7			
		4. 1·5	0/6			
		5. 2	2/2			
		6. 3·6	6/6			
		7. 5·2	2/2			
		8. 3·7	0/8			
		9. 2·2	0/6			
		10. 3·2	0/3			
		11. 2·2	0/8			
		12. 1	0/8			
		13. 0·5	0/8			
		14. 2	0/8			
		15. 2·5	0/8			
> 5 years	9	1. 2·7	0/7 Total 3/9	Not Done		
		2. 4	0/6			
		3. 2·2	1/7			
		4. 1·2	2/8			
		5. 1.4	1/7			
		6. 1·2	0/7			
		7. 1·5	0/8			
		8. 4	0/8			
		9. 1·2	0/8			

Results

Eleven biopsies showed viable bacilli and in two specimens, the strains were sensitive to the three drugs (clofazimine, dapsone and rifampicin). For the remaining nine strains, the inoculum was not sufficient to carry out drug sensitivity testing. Multiplication was not observed in 30 biopsy specimens (Table 1). Three years later, the 11 patients with proven growth were recalled for clinical and bacteriological assessments. One out of the 11 cases died and another one was lost to follow-up. Nine patients were clinically inactive and their skin slit smears were negative for AFB (Table 2).

Discussion

A trial comparing 18 monthly and 30 monthly doses of the World Health Organization recommended multibacillary therapy in 305 multibacillary leprosy patients in Malawi is described. Patients were randomly allocated to one of the two regimens following the 18th supervised dose of WHO/MDT.

The mean follow-up period was 3 years. No relapse was observed in either group.[1]

Several studies demonstrated that biopsies, or nasal secretions taken from patients having received a single dose of 600 mg of rifampicin usually failed to give growth of *M. leprae* in foot pads of mice,[2–6] whereas it took 3–6 months of daily treatment to obtain the same results with either dapsone alone or clofazimine.

In this study, we observed that the isolation of viable bacilli is not necessarily related to the duration of MDT or to the average BI. It also appears that there was a rapid clearing of bacilli following the discontinuation of therapy in some of our patients. Viable bacilli can be isolated from some patients after completion of WHO/MDT, but most patients can eliminate these bacilli without further chemotherapy and do not seem to be at great risk of relapse.

Table 2. Average BI of the nine multibacillary patients with poor BI reduction on long-term treatment with WHO/MDT and with proven viable bacilli

Exp. no.	Pre-treatment BI	Duration of treatment at time of enrolment (years)	BI status at time of enrolment	No. of AFB incubated	BI status after 3 years follow-up period
1	4	5	2·2	Not identified	0
2	5	4·4	5·2	10^4	0
3	5	4	2	Not identified 30 μl inc. of susp.	0
4	5	3·6	3·6	10^4	0
5	5	5	1·4	Not identified 30 μl inc. of susp.	0
6	6	4	2	10^4	0
7	6	2	4·7	10^4	0
8	6	7·2	1–2	Not identified 30 μl inc. of susp.	0
9	5	2	5	10^4	0

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References

[1] Results of a trial in Malawi. Are 18 doses of WHO/MDT sufficient for multibacillary leprosy? *Int J Lepr Other Mycobacterial Dis*, 1995; **63:** 1–7.
[2] Shepard CC, Levy L, Fasal P. Rapid bactericidal effect of rifampicin on *Mycobacterium leprae. Am J Trop Med Hyg*, 1972; **21:** 446–449.
[3] Shepard CC, Levy L, Fasal P. Further experience with the rapid bactericidal effect of rifampicin on *M. leprae. Am J Trop Med Hyg*, 1974; **23:** 1129–1134.
[4] Collaborative effort of the US Leprosy Panel (U.S.–Japan Co-operative Medical Science Programme) rifampicin therapy of lepromatous leprosy. *Am J Trop Med Hyg*, 1975; 475–484.
[5] Levy L, Shepard CC, Fasal P. The bactericidal effect of rifampicin on *M. leprae* in man. a) Single doses of 600, 900 and 1200 and b) daily doses of 300 mg. *Int J Lepr*, 1976; **44:** 183–187.
[6] Habtemariam HS, Guebre-Xaber M. Lack of viability of *Mycobacterium leprae* isolated from nasal secretions of lepromatous leprosy patients following daily rifampicin and DDS therapy. *Lepr Rev*, 1993; **64:** 312–315.

Lepr Rev (1999) **70,** 47–51

An assessment of the value of midfinger smears in multibacillary leprosy patients

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Summary In view of the different opinions on fingers as sites for persisting bacilli in multibacillary leprosy patients, it was decided to examine the midfingers for the presence of acid-fast bacilli (AFB) and establish its usefulness. Sixty-nine multibacillary leprosy patients, [lepromatous (LL) and borderline lepromatous (BL)] treated with multidrug therapy for fixed duration (2 years) were analysed. The bacillary load in the midfinger sites was lower when compared to that in the 'compulsory' (both earlobes) and 'optional' (four active lesions) sites. The midfinger bacterial index (BI) was higher among LL patients when compared to BL patients ($p < 0{\cdot}001$). However, the difference in mean BI in 'optional' and 'compulsory sites' was not significant. The overall fall in BI was gradual and on expected lines for all sites, including midfingers, during treatment and follow-up period. Except in one case, at no time were the smears from midfinger sites positive when all other sites were negative, and their inclusion did not contribute to the early detection of relapse. Furthermore, the collection of blood-free smears from this site is technically difficult and often painful for the patient. The inclusion of midfinger smears in this study in patients in South India did not contribute useful information to that which is routinely available from smears of earlobes and other active sites.

Introduction

Untreated lepromatous leprosy is characterized by the presence of a heavy load of bacilli from any area in the skin. Following adequate treatment with multidrug therapy (MDT), the bacterial load declines gradually. It has been reported by Ridley and Jopling[1] that in long-term treated patients, solid staining bacilli may sometimes be found in the slit skin smear from the dorsum of the finger (though there are no apparent lesions on the fingers) when other sites are bacteriologically negative. It has also been reported that finger smears are early indicators of relapses due to persisting bacilli.[3] There are other reports in the literature both for and against the superiority of finger smears over routine slit skin smears.[2–7]

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The aim of the present report was to examine the value of midfinger smears in multibacillary (MB) leprosy patients who were treated with fixed duration MDT (2 years) and followed up for a period of 60 months.

Materials and methods

MB leprosy patients with bacterial index (BI) of 2·5 or more (on six sites) admitted to a controlled clinical trial of MDT for fixed duration were the subjects.

Slit skin smears for the presence of AFB were taken from six sites, namely, both earlobes as 'compulsory' sites (CS) and four active lesions as 'optional' sites (OS) on admission, at 3 months, 6 months and thereafter every 6 months up to 60 months.[5]

Finger smears[2] were taken from the dorsum of both midfingers (MF) on admission, at 24 months and thereafter every 6 months up to 60 months. BI grading was done by the Ridley–Jopling method. Results from CS, OS and midfinger sites were compared at different time periods. Histopathological examination was done to confirm the clinical diagnosis.

Results

On admission, midfinger smears were taken from 99 patients. Thirty patients were excluded (nine died, 19 failed to attend or were non-cooperative, and two migrated) and the remaining 69 were analysed. Of the 69 patients, 32 (46%) were histopathologically classified as LL, 35 (51%) as BL and for two patients the classification was not available (clinically classified as BL and LLp).

MIDFINGERS VERSUS COMPULSORY SITES

On admission, in 36 (52%) of 69 patients, the mean BI in the CS sites was higher than in the midfingers. Only six (9%) had a higher mean BI in the midfingers than in the CS (Table 1).

Table 1. Midfingers versus 'compulsory sites' (mean BI) on admission

	'Compulsory sites'				
MF	2.0–	3.0–	4.0–	5.0–	Total
0·0	1	0	2	0	3
1·0–	0	2	2	0	4
2·0–	0	1	1	0	2
3·0–	1	0	10	4	15
4·0–	0	1	23	13	37
5·0–	0	2	2	4	8
Total	2	6	40	21	69

Table 2. Midfingers versus 'optional sites' (mean BI) on admission

	'Optional sites'				
MF	2.0–	3.0–	4.0–	5.0–	Total
0·0	2	0	1	0	3
1·0–	1	1	2	0	4
2·0–	0	0	1	1	2
3.0–	1	5	8	1	15
4·0–	1	6	27	3	37
5.0–	0	0	5	3	8
Total	5	12	44	8	69

MIDFINGERS VERSUS OPTIONAL SITES

While comparing midfinger smears with OS, it was found that 21 (30%) of 69 patients had higher mean BI in the OS and 13 (19%) had higher mean BI in the midfingers (Table 2).

For three patients (all BL cases), the BIs from midfinger smears were negative on admission as well as in the post-treatment period, whereas the BI from the CS and OS were positive up to 24 months.

COMPARISON OF MEAN BI AMONG LL AND BL PATIENTS

While there was no significant difference in the mean BI in CS and OS between the LL and BL group, the midfinger smear positivity among the BL patients was significantly less than that of LL patients ($p \leq 0{\cdot}001$) at all the time periods (Table 3).

The mean BI in the midfingers were found to be less than those of the CS and OS in both

Table 3. Comparison of the mean bacterial index (BI) among LL and BL patients

		0 month Mean BI	24 months Mean BI	Fall	60 months Mean BI	Fall
	CS	4·64 (3·5–5·5)	3·83 (1·0–5·0)	0·81	1·35* (0·0–4·0)	3·29
LL	OS	4·39	3·18	1·21	1·19*	3·20
($n = 32$)		(2·5–5·5)	(0·25–4·5)		(0·0–3·25)	
	MF	4·13 (2·0–5·0)	2·63 (0·0–4·0)	1·50	0·71* (0·0–3·0)	3·42
	CS	4·17 (2·0–5·5)	2·71 (0·0–6·0)	1·46	0·60 (0·0–3·5)	3·57
BL	OS	3·91	2·25	1·66	0·64	3·27
($n = 35$)		(2·0–5·0)	(0·0–4·25)		(0·0–3·5)	
	MF	3·17 (0·0–5·0)	1·70** (0·0–4·5)	1·47	0·30 (0·0–3·5)	2·87

Histopathology not done for two patients.
*One patient failed to attend at 60 months.
**MF smear not done for two patients.

Table 4. Comparison of the bacterial status at 60 months among midfinger, 'compulsory' sites and 'optional' sites

		CS		OS	
MF	*n*	Pos	Neg	Pos	Neg
Pos	24	17	7	22	2
Neg	44	22	22	22	22
Total	68*	39	29	44	24

*One patient failed to attend (FTA) at 60 months.

LL and BL groups during all the time points, though the rate of fall in the mean BI was similar in the LL and BL groups.

Of the 24 patients who were positive for midfingers, seven were negative for CS and two were negative for the OS at the end of 60 months. Of the 44 patients who were negative for midfingers, 22 were positive for CS and an equal number were positive for OS (Table 4). There was only a slight agreement (kappa = 0·18) between midfingers with CS, while the agreement between midfingers with OS was fair (kappa = 0·35).

Discussion

It has been reported by Ridley *et al.*[1] in a study on 30 LL patients that midfinger sites had high bacterial load and contained the greatest number of solid staining bacilli. This was all the more striking as there were no lesions on the fingers. In India, Hiramalini *et al.*,[2] in a study on 41 LL patients, found that the fingers were the sites with the highest bacillary load and more productive than the earlobes. However, Macrery,[6] in the Lepra Control Project, Malawi during July 1986 to May 1987, showed that the finger smear was generally not useful and their BI results were different from those previously published. In his study based on 278 smears, in 71·2% of the smears the BI of the finger site was the lowest.

In our study among 69 patients, the bacillary load was less in the midfingers when compared to the bacillary load in the CS and OS. When LL and BL patients were compared, the midfinger BI value was higher among LL patients. However, the difference in the mean BI among the LL and BL patients in the compulsory and optional sites was not significant.

In our study, the overall fall in BI was gradual and on expected lines for all the sites, including the midfingers, during treatment as well as the follow-up period. All the patients have been followed up for up to 60 months. We did not find any solid bacilli in the midfingers as reported by earlier authors. We have also not come across any relapse so far. In our earlier study on multibacillary leprosy patients,[8] there were two relapses at 162 and 177 months after 4–5 years of negativity and in both these patients the BI readings from the midfinger sites were negative in the pre-relapse as well as in the relapse period, although the routine skin smears became positive at the time of relapse (BI 2·75 and 1·33, respectively).

There are many practical difficulties in taking midfinger smears because as the years pass by, subcutaneous tissues are replaced by fibrous tissues and therefore the skin over the fingers become firm. Further, it is not always possible to pinch sufficient thickness of skin and most

of the time it becomes difficult to collect blood-free tissue material for smears. Moreover, the procedure is painful for the patient because of the high sensitivity of the area. As the BI value is lower in the midfingers than in the other sites, and also since they are not early indicators of relapse, we suggest that it is better to restrict the taking of multiple smears, when indicated, from the earlobes and other active 'optional' sites.

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References

[1] Ridley MJ, Jopling WH, Ridley DS. Acid-fast bacilli in the fingers of long-treated lepromatous patients. *Lepr Rev*, 1976; **47**: 93–96.
[2] Hiramalini S, Joseph NA, Chacko CJG. Concentration and persistence of bacilli in the fingers and toes of patients with lepromatous leprosy. *Lepr Rev*, 1978; **49**: 223–229.
[3] Jopling WH, Rees RJW, Ridley DS, Ridley MJ, Samuel NM. The fingers as sites of leprosy bacilli in pre-relapse patients. *Lepr Rev*, 1979; **50**: 289–292.
[4] Jopling WH. A report on two follow-up investigations of the Malta Project. *Lepr Rev*, 1986; **57**: 47–52.
[5] Ahmed HA, Belehu A, Stoner G., Touw J., Atlaw T. Selection of sites for slit-smears. *Lepr Rev*, 1979; **50**: 283–287.
[6] Macrery RT. Slit-skin smears from the fingers in leprosy. *Lepr Rev*, 1988; **59**: 360–361.
[7] Warndorff-Van Diepen T. Smear site selection with particular reference to the fingers. A study of 244 long treated lepromatous patients. *Int J Lepr*, 1982; **50**: 39–42.
[8] Thomas A, Hari L, Nagarajan M, Prabhakar R. Relapse during long term follow-up with drug susceptible *M. leprae* among multibacillary leprosy patients treated with multidrug therapy regimens; case report. *Int J Lepr*, 1995; **63**: 391–394.

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Increased levels of nitric oxide metabolites in urine from leprosy patients in reversal reaction

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Summary We measured the metabolites of NO [nitrite (NO_2^-) and nitrate (NO_3^-)] in urine from Ethiopian patients suffering from leprosy. The urinary level of NO_2^-/NO_3^- in a group of healthy Ethiopians was $1020 \pm 471\,\mu M$ ($n = 22$). Leprosy patients in reversal reaction had significantly higher levels of NO_2^-/NO_3^- ($1817 \pm 492\,\mu M$, $p < 0{\cdot}001$, $n = 12$) than both the control group and leprosy patients who were not in reversal reaction ($1079 \pm 446\,\mu M$, $n = 12$). We conclude that the reversal reaction in leprosy is associated with increased urinary levels of nitric oxide metabolites.

Introduction

Leprosy according to WHO definitions presently affects approximately 1 million individuals worldwide[1] and the disease primary involves the skin and peripheral nerve system.[2] Leprosy is classified according to immunity as a polar disease with a spectrum ranging from the tuberculoid (TT) to the lepromatous (LL) form, with the borderline forms in between.[3] The term 'reaction' in leprosy is used to describe the appearance of symptoms and signs of acute inflammation. Type 1 reversal reactions occurring in borderline cases are associated with an increase in cell-mediated immunity, and nerve damage from neuritis may be rapid and severe.[2]

Inducible NO synthase (iNOS) is responsible for the synthesis of NO and L-citrulline from L-arginine by activated macrophages. NO is highly unstable and decays to its stable end products nitrate (NO_3^-) and nitrite (NO_2^-), which are eliminated in the urine.[4] Evidence is accumulating that nitric oxide (NO) produced by macrophages is an important factor in host defence against intracellular pathogens such as *M. tuberculosis*[5–7] and *M. leprae*.[8,9] A recent

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report has described the presence of iNOS in skin biopsies from patients undergoing reversal reaction.[10] The aim of this study was to investigate the urinary levels of nitric oxide metabolites in patients with leprosy in the reactional stage of the disease.

Materials and methods

MATERIALS

These were: *Aspergillus* nitrate reductase (Boehringer Mannheim, Freiberg, Germany), NADPH as the tetrasodium salt (Boehringer Mannheim), sulphanilic acid (Merck, Darmstadt, Germany), sodium nitrate (Merck), sodium nitrate (Sigma Chemical Co., St Louis, USA), *N*-(1-naphthyl) ethylenediamine (Sigma) and phosphate buffered saline (PBS).

COLLECTION OF URINE SAMPLES

Leprosy patients in the reactional stage were admitted to the wards of ALERT Hospital, Addis Ababa, Ethiopia because of reversal reaction in leprosy [$n = 12$, males $= 7$, females $= 5$, average age 31 ± 12 years old, age range 14–54, borderline lepromatous (BL $= 8$), borderline tuberculoid (BT $= 4$)]. All patients were in reversal reaction (type I reaction) and were differentiated clinically from patients with erythema nodosum leprosum (type II reaction). The samples from these patients were obtained within 2 weeks after admission and all patients were on steroid treatment. The patients did not show clinical signs of any co-existing disease and all had negative stool samples by microscopy. Urine samples were also collected from 12 patients suffering from borderline forms of leprosy [borderline lepromatous (BL $= 2$), borderline tuberculoid (BT $= 10$)] who were not undergoing reversal reaction (males $= 5$, females $= 7$, average age 38 ± 14 years old, age range 18–63). The control group for urinary levels of NO_2^-/NO_3^- consisted of 22 healthy Ethiopian individuals ($n = 22$, males $= 13$, females $= 9$, average age 36 ± 9 years old, age range 20–55). All urine samples were morning urine samples and were stored at $-20°C$ until analysed. The study was approved by the ethical committee at Armauer Hansen Research Institute and ALERT Hospital, Addis Ababa, Ethiopia.

ANALYSIS OF NITRITE AND NITRATE

The sum of the NO_3^- and NO_2^- concentrations in urine was determined essentially as described by Giliam *et al.*[11] Urine was diluted in PBS. Nitrate in the samples was reduced to NO_2^- by incubating the sample with 10 μl nitrate reductase from *Aspergillus* (10 IU/ml) and 10 μl nicotinamide adenine dinucleotide phosphate (reduced NADPH; 1 mM) for 2 h at 37°C. The NO_2^- level was then determined by the Griess reaction. The final reaction volume of 1 ml contained 728 μl HCl (0·45 M), 86 μl sulphanilic acid (2 mg/ml), 86 μl *N*-(1-naphthyl) ethylenediamine (1 mg/ml) and 100 μl of the diluted urine sample. The urine samples were then analysed on a ELISA multiwell reader (Titertec Multiscan Plus) at 542 nm.

STATISTICAL ANALYSIS

Statistical evaluation was performed with the Mann–Whitney *U*-test for comparison between groups. Data are presented as mean $\pm$ SD.

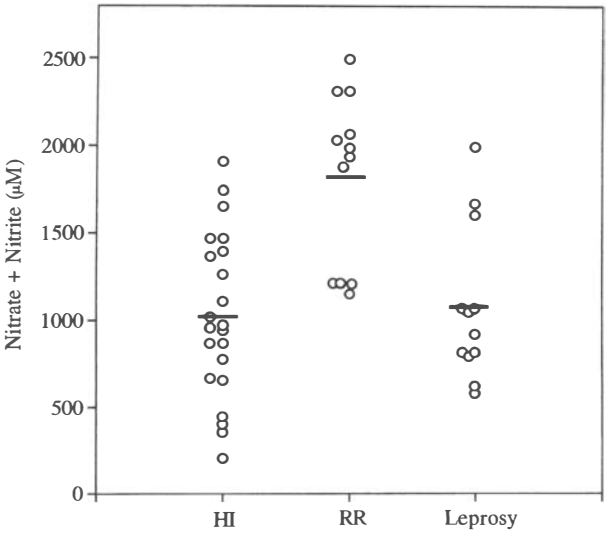

Figure 1. Urinary levels of nitrate and nitrite (the mean is represented by bold lines) in: healthy Ethiopian individuals (HI, $n = 22$), leprosy patients in reversal reaction (RR, $n = 12$) and leprosy patients who were not undergoing reversal reaction (Leprosy, $n = 12$).

Results

The control group consisted of apparently healthy Ethiopian individuals. The mean urinary excretion of NO_2^-/NO_3^- in this group of 22 individuals was found to be $1020 \pm 471\,\mu M$ (range 198–1907) (Figure 1). Urine was obtained from leprosy patients admitted to the ALERT Hospital, Addis Ababa, Ethiopia because they were undergoing reversal reaction. Leprosy patients in reversal reaction had significantly higher levels of NO_2^-/NO_3^- ($1817 \pm 492\,\mu M$, $p < 0{\cdot}001$, $n = 12$) than both the control group and leprosy patients who were not undergoing reversal reaction ($1079 \pm 446\,\mu M$, $n = 12$).

Discussion

Nitric oxide produced by the macrophage has been suggested to play an important role in the host response to pathogens targeting the macrophage such as *M. leprae*.[10,12,13] The metabolites of NO, NO_3^- and NO_2^-, have been used as a measurement of the production of NO in serum and urine from humans in various diseases such as cancer,[14] malaria[15] and children with coeliac disease.[16] In humans the sources of NO_2^-/NO_3^- are food, air (NO_2) and endogenous synthesis,[17] In this study, there were no restrictions of NO_2^-/NO_3^- in the diet in any of the study groups, and increases of NO_2^-/NO_3^- might be influenced by a diet rich in nitrate-containing food. However, in this study there was a strong correlation between increased levels of NO metabolites and the reactional stage of leprosy, where NO has been suggested to play a role in the host response. Our results are also consistent with a recent report where 13 out of 15 leprosy patients undergoing reversal reaction were iNOS positive in skin biopsies, whereas BT patients and healthy controls were completely negative.[10] The

reactional stage of leprosy is a stage of the disease associated with acute inflammation.[2] Patients with ulcerative colitis, Crohn's disease and coeliac disease also have increased levels of nitrate and nitrite during active stages when the degree of inflammation is high, but normal levels of nitrate and nitrite between these stages.[16,18] Thus, there seem to be a connection between NO production and acute inflammation. Further studies are required to evaluate raised levels of urinary NO metabolites as a predictive marker of reversal reactions in leprosy. We conclude that leprosy patients in reversal reaction have increased urinary levels of NO metabolites.

References

[1] Editorial. *Lepr Rev*, 1997; **68**: 195–200.

[2] Gelber HG. Leprosy (Hansen's disease). In: Mandell GL, Bennet JE, Dolin R. Mandell, eds. *Douglas and Bennett's principles and practice of infectious diseases*. Churchill Livingstone, New York, 1995; 2243–2250.

[3] Ridley DS, Jopline WH. Classification of leprosy according to immunity. A five group system. *Int J Lepr*, 1966; **34**: 255–273.

[4] Änggård E. Nitric oxide: mediator, murderer and medicine. *Lancet*, 1994; **343**: 1199–1206.

[5] Chan J, Xing Y, Magliozzo RS, Bloom BR. Killing of virulent *Mycobacterium tuberculosis* by reactive nitrogen intermediates produced by activated murine macrophages. *J Exp Med*, 1992; **175**: 1111–1122.

[6] Chan J, Tanaka K, Carrol D, Flynn J, Bloom BR. Effects of nitric oxide synthase inhibitors on murine infection with *Mycobacterium tuberculosis*. *Infect Immun*, 1995; **63**: 736–740.

[7] Nicholson S, Bonecini-Almeida M, Lapa e Silva JR, Nathan C, Xie Qiao-wen, Mumford R, Weidner JR, Calaycay J, Geng J, Boechat N, Linhares C, Rom W, Ho JL. Inducible nitric oxide synthase in pulmonary alveolar macrophages from patients with tuberculosis. *J Exp Med*, 1996; **183**: 2293–2302.

[8] Adams LB, Franzblau SG, Vavrin Z, Hibbs Jr JB, Krahenbuhl JL. L-Arginine-dependent macrophage effector functions inhibit metabolic activity of *Mycobacterium laprae*. *J Immunol*, 1991; **147**: 1642–1646.

[9] Khare S, Bhutani LK, Rao DN. Release of reactive nitrogen intermediates from the peripheral blood-derived monocytes/macrophages of leprosy patients stimulated in vitro by tuftsin. *Lepr Rev*, 1997; **68**: 16–24.

[10] Khanolkar-Young S, Snowdown D, Lockwood DNJ. Immunocytochemical localisation of inducible nitric oxide synthase and transforming growth factor-β in leprosy lesions. *Clin Exp Immunol*, 1998; **113**: 438–442.

[11] Giliam MB, Sherman MP, Griscavage JM, Ignarro LJ. A spectrophotometric assay for nitrate using NADPH oxidation by *Aspergillus* nitrate reductase. *Anal Biochem*, 1993; **212**: 259–265.

[12] MacMicking J, Xie Qiao-Wen, Nathan C. Nitric oxide and macrophage function. *Annu Rev Immunol*, 1997; **15**: 323–350.

[13] DeGroote MA, Fang FC. NO inhibitions: antimicrobial properties of nitric oxide. *Clin Invest Dis*, 1995; **21**: S162–165.

[14] Hibbs Jr JB, Westenfelder C, Taintor R, Vavrin Z, Kablitz C, Baranowski RL, Ward JH, Menlove RL, McMurry MP, Kushner JP, Samlowski WE. Evidence for cytokine-inducible nitric oxide synthesis from L-arginine in patients receiving interleukin-2 therapy. *J Clin Invest*, 1992; **89**: 867–877.

[15] Anstey NM, Weinberg JB, Hassanali MY, Mwaikambo ED, Manyenga D, Misukonis MA, Arnelle DR, Hollis D, McDonald MI, Granger DL. Nitric oxide in Tanzanian children with malaria: inverse relationship between malaria severity and nitric oxide production/nitric oxide synthase type 2 expression. *J Exp Med*, 1996; **184**: 557–567.

[16] Sundqvist T, Laurin P, Fälth-Magnusson K, Magnusson K-E, Stenhammar L. Significantly increased levels of nitric oxide products in urine of children with celiac disease. *J Pediat Gastroenterol Nutr*, 1998; **27**: 196–198.

[17] Green LC, De Luzuriaga KR, Wagner DA, Rand W, Istfan N, Young VR, Tannenbaum SR. Nitrate biosynthesis in man. *Proc Natl Acad Sci USA*, 1981; **84**: 6369–6373.

[18] Oudkerk Pool M, Bouma G, Visser JJ, Kolkman JJ, Tran DD, Meuwissen SGM, Pena AS. Serum nitrate levels in ulcerative colitis and Crohn's disease. *Scand J Gastroenterol*, 1995; **30**: 784–788.

Lepr Rev (1999) **70,** 56–62

SPECIAL ARTICLE

Results of a 1 year Special Action Project for the Elimination of Leprosy (SAPEL) in poorly accessible areas of Akwa Ibom State, Nigeria

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Summary This article reports the outcome of a Special Action Project for the Elimination of Leprosy (SAPEL), including the implementation of multidrug therapy (MDT) in difficult situations in Akwa Ibom State in Nigeria. Twenty-two fishing villages and five communities in areas of gully erosion participated in the project from August 1996 to September 1997. Seven new cases were detected and treated with MDT. Twenty-one out of 22 defaulters examined resided in the mainland part of the project area and not in the fishing villages. Considerable difficulties were encountered with regard to the exorbitant cost of transport, physical attacks on the teams and the lack of reliable information on population figures for the project area. The discussion includes attention to the cost-effectiveness of the SAPEL approach under the conditions described and the need to develop better monitoring of treatment and community participation in poorly accessible areas.

Introduction

For over 6 decades, efforts to control leprosy as a public health problem in Akwa Ibom State, southeast Nigeria, were limited to the mainland regions. Problems of inaccessibility and poor communication prevented penetration of areas of severe gully erosion, the creeks and fishing islands scattered around the state. For these reasons, Akwa Ibom State leprosy control programme adopted the WHO Special Action project for the Elimination of Leprosy (SAPEL)[1] initiative in 1995, to extend multidrug therapy (MDT) to leprosy patients living in poorly accessible areas of the state; and to verify a suspicion that the majority of defaulting patients hide in the fishing communities. This paper relates the outcome of MDT implementation in 27 villages in three Local Government Areas or districts, in Akwa Ibom State. This is the first time any kind of leprosy control has been carried out in the 22 fishing communities that participated in the SAPEL project. This account covers the period from August 1996 when the project commenced to December 1997 when multibacillary (MB) patients were discharged from MDT.

BACKGROUND

Akwa Ibom State, one of the 36 states of the Federal Republic of Nigeria, is situated on the

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southeastern corner of the country and covers a land area of about 5862 km^2. The shape of the state approximates that of a triangle. Its boundaries are Rivers State and Abia State to the west; Cross-River State to the east; and the Atlantic Ocean to the south. The 1997 estimated population of the state is 2·79 million, projected from 1991 census figure of 2·36 million using an annual growth rate of 2·83%.[2] The majority of the population are rural dwellers. Two main ethnic groups, namely the Annangs and the Ibibios, inhabit the state. The predominant occupations are agriculture and fishing.

The climate of the state is described as tropical rainy type. There are two distinct seasons: the dry season from November to March during which the cool and dust laden Harmattan wind blows, and the rainy season from April to October. On the basis of terrain and landform types,[3] two major geomorphic regions are identified within Akwa Ibom State. These are the flat coastal plain regions characterized by rivers and ox-bow lakes in the southern part of the state, and the high rising dissected regions characterized by ravines and steep-sided hills in the northern part of the state.

Administratively, the state is divided into 31 Local Government Areas (LGAs) with population range of 56,000–235,000 people. For purposes of health care delivery, the state is divided into three health zones comprising about 10 LGAs per zone. The Local Government Area is the operational level of primary health care (PHC) implementation in Nigeria,[4] including leprosy control. There are 230 health facilities offering primary care in Akwa Ibom State.[5] Thirty-six (16%) of these 230 health facilities are leprosy clinics offering MDT services. Furthermore, 11 out of the 36 leprosy clinics are vertical (leprosy-only) clinics. The remaining 25 leprosy clinics operate as semi-integrated clinics within PHC facilities and are run by specialized leprosy staff. General health personnel attached to these 25 semi-integrated leprosy clinics are yet to be functionally involved in leprosy control activities.

BRIEF LEPROSY SITUATION

In 1926, the Scottish Presbyterian Mission built Nigeria's first leprosy hospital in Itu LGA in the north of Akwa Ibom. The Itu Hospital played a pioneering role in leprosy research and treatment during the use of Chaulmoougra oil and dapsone in the treatment of leprosy. Unfortunately, this hospital now lies in ruins after the Nigerian Civil war of 1967–1970. A sister-hospital established in 1932 by Qua Iboe Fellowship, Belfast, and situated in Etinan LGA, south of Akwa Ibom, continued the functions of Itu Hospital. The Qua Iboe Church Leprosy Hospital serves as the present day referral centre for leprosy control in Akwa Ibom State. For reasons of poor communication and inaccessibility, efforts to control leprosy as a public health problem in the state using dapsone monotherapy were limited to the mainland parts. The creeks and fishing islands were difficult to penetrate without canoes.

The WHO/MDT was introduced in the state in 1982. By December 1993, Akwa Ibom State had achieved 100% MDT coverage of clinics situated in the mainland parts of the state. Following the implementation of MDT, the registered prevalence of leprosy in Akwa Ibom decreased from about 2000 patients in 1982 to 225 by October 1997. The MDT completion rates in 1996 were poor in both MB (60%) and paucibacillary (PB) (73%) patients. The grade 2 disability rate amongst new cases in 1996 was 16·8%.[6] The MDT completion cohort and disability figures for the end of 1997 were not available when this report was written.

SITE OF THE PROJECT

Akwa Ibom State adopted the SAPEL initiative in December 1995 to extend MDT services to poorly accessible communities in a total of 12 LGAs in state. Because of the scattered nature of fishing communities and the vastness of the area covered by the 12 LGAs, extension of MDT to poorly accessible communities was to be executed in phases. Three LGAs served as sites for the first phase of the project, namely, Ikono and Itu LGAs in the north and Uruan LGA in the east central part of the state. Ikono LGA lies within the high rising regions characterized by gully erosions and ravines that make road transportation difficult throughout the year. On the other hand, Uruan LGA lies within the flat coastal plains traversed by rivers and lakes that are only accessible by canoe. Itu LGA lies between the two land form regions.

The population of the three LGAs is approximately 400,000. The 1996 end-of-year prevalence of leprosy in the project area was 2·5/10,000 population.[6] There was a total of 72 defaulters in Akwa Ibom State in January 1996. Uruan, Itu and Ikono LGAs contributed 59 (82%) of the 72 defaulters. In addition to extending MDT to the project area, the project attempted to verify the suspicion advanced by the State leprosy control officer that the majority of defaulters from the mainland hide in the fishing islands of the project area.

Materials and methods

A SAPEL project to extend MDT to poorly accessible communities in Akwa Ibom State commenced in August 1996 and lasted until September 1997. Leprosy control supervisors of the project LGAs selected a total of 29 villages, but 27 of them participated in the project. Based on WHO inclusion criteria, five out of the 27 villages that participated were purposely selected from areas of gully erosion, whereas the remaining 22 villages were selected from fishing communities, as they were not covered by health services. No form of leprosy control service had ever been carried out in the 22 fishing communities. The tribal population of these fishing communities is also nomadic in lifestyle, migrating from island to island at least 8 months of the year in search of fertile fishing grounds. The project was therefore scheduled to start in the month of August when the rains are heaviest and the fishermen remain in their homes. Letters explaining the reasons for the project were addressed to community leaders, soliciting their cooperation and participation in the project.

The objectives of the project were: (i) to determine the prevalence of leprosy in the selected area, (ii) to verify a suspicion that the majority of defaulting patients hide in the fishing islands and (iii) to ensure that patients enjoyed uninterrupted MDT service in the difficult situations of the project area by involving village heads in control activities.

The project was subdivided into two parts; (a) community surveys and defaulter tracing to achieve objectives (i) and (ii); and (b) 1-year follow-up period, to achieve objective (iii). A team of eight people comprising two medical officers (MOs) and six LGA leprosy supervisors participated in the project. The leprosy supervisors selected had more than 15 years of field experience in leprosy control, while the MOs [one of who is the author and the other was the State Leprosy Control Officer (SLCO)] had 4 years of experience. The SLCO participated in the project only during the survey, while the author and the six leprosy supervisors took part in the surveys and the follow-up of the patients detected, but on a part-time basis (combining the project with regular control activities). The team penetrated the riverine areas by use of canoes and the high rising areas by the use of motor cycles.

Prior to the community surveys, the supervisors trained village leaders in the diagnosis of leprosy, availability and efficacy of MDT and the advantages of early detection, by guided discussions lasting about 45 min. After the training, a house-to-house survey of the community took place, with the active participation of the village heads in the examination of people present. Diagnosis of a case of leprosy and classification were carried out by clinical examination following the WHO guidelines.[7] The MOs re-examined suspect cases presented by the village heads. Confirmed cases were treated with MDT without delay.

During the follow-up period, village heads monitored the treatment of confirmed cases until the supervisor's next visit. The village heads were given MDT blister calendar packs lasting up to 4 months to ensure that the patients got an uninterrupted supply of drugs. The supervisors returned to replenish the MDT blister calendar packs of village leaders and chart the progress of patients every 2 months.

Only the supervisors carried out defaulter tracing during the project. MOs did not take part in the defaulter tracing. At least two visits for each defaulter were carried out before most of them were found and examined.

At the start of the project, cure was defined as completion of fixed duration WHO MDT. PB patients were required to take six doses within 9 months. MB cases were expected to take 24 doses of MDT within 36 months before they were released from treatment (RFT). However, the adoption by Nigeria in December 1997 of the WHO recommendations[8] for shortening the duration of treatment for MB cases from 24 doses to 12 doses of MB-MDT led to a revision of the RFT protocol for MB patients.

At the expiration of the project in September 1997, responsibility for funding and supervision of MDT activities in the project area was transferred to The Leprosy Mission, the ILEP Coordinator of leprosy control in Akwa Ibom State.

Results

CASE FINDING

Twenty-seven villages took part in the project. Two villages involved in inter-communal conflict did not participate. The surveys lasted for 30 days. A total of 6129 people from 768 households was examined. This population comprised 3621 children and 2508 adults; see Table 1 for details. Table 2 shows the age, classification, disability grades, and treatment outcomes of patients. Seven new patients (four PB and three MB) were detected during the survey. Only one child was detected. All four PB patients had single, active lesions. All seven patients took their treatment regularly. By December 1997, PB patients had been RFT after taking six doses of MDT. The MB patients had received at least 12 doses of MDT and were

Table 1. Distribution of examined population by age and sex

	0–14 years	15+ years	Total	%
Male	1743	1712	3455	56·4
Female	1874	796	2674	43·6
Total	3621	2508	6129	100
(%)	(59·1)	(40·9)	(100)	–

Table 2. Classification, disability grade and age of new patients detected

Sex	Age (years)	Classification	Disability grade	Treatment outcome
M	14	PB	0	RFT
M	22	MB	0	RFT
F	33	PB	0	RFT
M	35	PB	0	RFT
M	45	MB	0	RFT
F	45	PB	0	RFT
F	50	MB	0	RFT

RFT following a 1997 WHO recommendation[8] for treating MB patients with 12 doses of MDT.

DEFAULTER RETRIEVAL

Table 3 shows the outcome of defaulter retrieval during the project. Fifty-two out of 59 defaulters were selected for retrieval. Seven patients were excluded due to incomplete records. Only 22 of the 52 defaulters on the mainland register could be traced and examined. Some of the remaining 30 patients had either died or left the control area to go to neighbouring states looking for jobs. Only one of the 22 defaulters examined was resident in the fishing community. The remaining 21 defaulters were found on the mainland parts of the project area. The reason for defaulting given by the majority of patients was the belief that their disease was cured. After careful consideration by the project team, all 22 patients were RFT as their skin lesions were inactive. By December 1996, only four defaulters were on the register. These were patients living in the two warring communities that did not participate in the project.

LIMITATIONS AND DIFFICULTIES ENCOUNTERED DURING THE SURVEY

(i) The total population listed in the case finding section above is the number of people

Table 3. Outcome of defaulter retrieval

Category	Number of patients	Percentage
Number of defaulters before tracing	52	100
Number RFT (cured)	22	42·3
Number re-admitted for MDT	0	0
Number who died	6	11·5
Number living in warring communities	4	9·6
Number who left control area to neighbouring states[a]	12	23·1
Number labelled out of control (no information available)[a]	8	15·4

[a]These categories of patients were removed from the register at the end of 1996. Number of defaulters in the project area at the end of 1996 = 4. Number of defaulters in Akwa Ibom State by 31 December 1997 = 7.

examined during the survey. Official (enumerated) population figures of the 27 communities in the project area were not available from the office of statistics. The population estimates of 23,640 given by village leaders were considered unreliable by the survey team, judging from the number of houses and people observed during the surveys.

(ii) The survey team was attacked and molested by youths who believed the team were spies from a neighbouring, rival community.

(iii) Under the local conditions described, the cost of water transportation that consumed approximately 25% of the total project funds ($12,179) was exorbitant, perhaps due to the scarcity of petrol used to power boats used during the project and because most of the fishing villages were out of routes commonly travelled by commercial water transport operators.

(iv) The nomadic lifestyle of the fishermen, who migrate in search of fertile fishing grounds, made follow-up of one patient difficult.

Discussion

It is noteworthy that all seven new patients were detected at very early stages and without disabilities. The compliance of patients to MDT without default emphasizes the positive role played by the village leaders in leprosy control on difficult situations of the project. This re-affirms previous reports by Ahmed and El Tahir[9] from Sudan, and Schäffer and Gakaitangou[10] from Chad.

The discovery of 21 of the 22 examined defaulters on the mainland part of the project area is a departure from the expectations of the project team. This result disproves the suspicion that the majority of defaulters hide in fishing islands and questions the practice of routine defaulter tracing in the mainland prior to SAPEL.

The detection of only seven new patients during the project should be interpreted with caution. On the one hand, the few numbers of patients detected appears to suggest that the backlog of untreated or hidden cases in the project area may be smaller than the backlog of untreated cases in other parts of the state which are easily accessible, mainland communities. These easily accessible, mainland communities contributed 112 (94%) of new cases detected in 1996 and 125 (100%) new cases detected in 1997 in Akwa Ibom State.

On the other hand, the detection of seven new cases in a population of 6129 implies an incidence rate of approximately one case per 1000 people examined, suggesting that neglect of such populations could, in future, contribute a significant proportion of new cases detected and may affect the attainment of sustenance of the WHO elimination target of prevalence of less than one case/10,000 population in Akwa Ibom region. The author is, however, unable to draw definite conclusions from this low number of new cases, as the project area represented only 25% of poorly accessible regions of Akwa Ibom State.

Recommendations

Judging by the small number of patients detected in the fishing communities, the limitation posed by exorbitant transport costs and the scarcity of funds to carry out such projects in developing countries, the author recommends that future leprosy control work in difficult situations in Akwa Ibom State give priority attention to (i) LGs in the northern part of the state where leprosy is reported to be hyper-endemic[11] and the cost of transportation is affordable

using motorcycles; (ii) better monitoring of patient treatment and prompt retrieval of absentees to prevent the occurrence of alarming numbers of defaulters; (iii) intensive and continuous community education using the radio to encourage early case detection and (iv) active community participation in the planning and implementation of MDT projects to ensure sustainability.

Acknowledgements

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References

[1] WHO. Action Programme for the Elimination of Leprosy. Leprosy Elimination Campaign (LEC) and Special Action Projects for the Elimination of Leprosy (SAPEL). *Questions and answers.* World Health Organisation, Geneva, 1997. WHO/LEP/97.3.
[2] *Annual Abstract of Statistics* 1996 edition. Federal Office of Statistics, Lagos, Nigeria, pp 27–29.
[3] Peters SW, Iwok ER, Uya OE. *Akwa Ibom State—the land of promise—a compendium.* GABUMOH Publishing Company, Yaba, Lagos, Nigeria, 1994: 239–244.
[4] WHO. *Local government focused acceleration of primary health care: the Nigerian experience. Report of a WHO review.* WHO, Geneva, 1992: 3.
[5] Akwa Ibom State Ministry of Health Statistics on Primary Health Care, 1995.
[6] Annual Report. Akwa Ibom State Leprosy Control Programme, 1996.
[7] WHO. *A guide to elimination of leprosy as a public health problem*, 1st edition. WHO/LEP/95.1, 1995: 15–21.
[8] WHO. *Final draft of WHO Expert Committee on Leprosy*, 7th Report, 1997: 17–18.
[9] Ahmed KM, El Tahir MS. Role of village leaders in the implementation of multidrug therapy for leprosy, Sudan—a pilot study in the Angasana Hills. *Lepr Rev*, 1996; **67:** 39–46.
[10] Gakaitangou F, Schäffer J. Comment: implementing multidrug therapy in areas not covered by the health services—some experiences from Chad. *Lepr Rev*, 1997; **68:** 90–91.
[11] Brightmer MI. New cases of leprosy in the Cross River Region, Nigeria. *Lepr Rev*, 1990; **61:** 273–281.

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FURTHER EDUCATION

Management of plantar ulcers in leprosy

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Introduction

The aim of this article is to promote and encourage ulcer care at the lowest possible level, as near to the patient's home as possible, and to stimulate paramedical workers and physicians in peripheral units to take responsibility for such treatment.

Traditionally surgeons, often working full time in leprosy institutions, in vertical leprosy programmes have given ulcer care. As integration proceeds, focusing on multi-drug therapy, the priority for care after cure in programmes gets a lower profile. There is then an increasing need for empowering patients with the responsibility for their own ulcer prevention, and empowering peripheral health units for basic surgical treatment of ulcers.

The focus of this article is on basic care of foot ulcers in leprosy. The principles and methods presented aim at solving the problems of ulcer formation by the simplest possible procedures, which can be easily taught to medical staff at different levels. The details of surgery are presented in a subsequent article.

Danger of plantar ulceration and its prevention

Peripheral nerve damage results in loss of sensory and motor function of the affected nerve, the posterior tibial and lateral popliteal nerves in the case of the foot. Loss of sensation, and the resulting loss of protective sensation such as touch, pain pressure and temperature discrimination results in increased vulnerability of the affected hands and feet to injury and normal daily activities become hazardous. Loss of sweating, due to disturbed autonomic function, decreases the protective quality of the skin. Paralysis of intrinsic and extrinsic muscles of the hands and feet alters the distribution of the stress on the palm of the hand and the sole of the foot during activity (prehension and weight bearing). All this leads to deterioration of soft and bony tissues. The various sequelae are (1) soft tissues: reduced visco-elasticity, atrophy, ulceration, tenosynovitis, (2) bones: decalcification, absorption, osteitis and (3) joints: subluxation, dislocation, osteoarthritis, and tarsal disintegration. Finally, deformities develop, first mobile and later fixed.

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Nerve damage and plantar ulcers

Loss of motor function leads to:
paralysis of muscles → imbalance of muscular forces → deformity and disability
deformity → increased weight bearing on some areas.
Loss of sensory function results in:
Loss of touch, pain, temperature sense → loss of protective sense →
→ increased chances of injury, burn, continued pressure → ulceration.
Loss of autonomic function leads to:
Loss of sweating → diminished resistance to injury and infection.
Early detection and treatment can prevent nerve involvement.

Plantar ulceration and its after effects can be prevented by:

- Change of lifestyle: by health education, and self-care training.
- Daily skin treatment: by soaking in water and greasing with oil or ointment.
- Protective devices: these include footwear together with thorn and nailproof outer sole that protects from external injury, orthotic devices like arch support, weight relieving metatarsal pads, and others that protect from internal pressure, that distribute weight bearing over the whole sole, and protect vulnerable areas of the foot from stresses.
- Preventive and rehabilitation – surgery: in many leprosy programmes surgery is not available for patients. Existing leprosy institutions are few, and far away; many patients in need of surgery cannot travel a long distance for treatment. Moreover, many programmes do not have access to surgically trained staff.

Surgery in ulcer management involves more than performing debridement, sequestrectomy and amputations. *Every intervention should aim at preventing further destruction, and upgrading of the affected limb.*

Ulcer formation

Understanding the reasons and mechanisms for tissue destruction and ulceration is essential for understanding the methods of management. Examining a foot will reveal a story to the attentive observer. This story may deviate from the story the patient is telling, which is of interest since it is crucial that the patient understands how ulcers happen to avoid their recurrence. An enlightened patient is the best contributor to successful ulcer prevention.

Ulcers:

are the result of:
Deformity and/or loss of protective sensation
are caused by:
Repetitive moderate stress
Direct trauma
Pressure causing ischaemia
Burn injury
Walking on infected feet

Where are the plantar ulcers?

Foot :3/4
Hindfoot:1/4
Fifth metatarsal base: 1/8
Heel 1/8
Ulcers on the heel and under the fifth metatarsal base are high-risk ulcers

PRINCIPAL CAUSES OF ULCERS

Repetitive moderate stress

Normal sensation prevents overuse of the foot. In the absence of sensation, the foot is overused; the patient accumulates tissue damage which goes *unnoticed* until a breakdown occurs. Too much walking gives rise to a 'hot spot' and swelling at the site of maximum stress. This injury is *still reversible if the foot is rested at this stage*. Further walking causes tissue death and a deep infected ulcer. The patient says that 'an ulcer suddenly occurred', without any injury. He tells the truth, for this is a 'within-out ulcer'.

Direct trauma

Examples are: thorn-pricks; thorns penetrate the sole of the shoe. Stones in the shoe are not felt and cause injury. Stones, nails and similar objects hitting during walking or working is another cause.

Pressure causing ischaemia

Pressure lasting an appreciable time causes local ischaemia. Ulcers of this kind are situated at harder areas at the side of the foot, or the dorsum, or the knuckles of the toes. An example is a shoe bite and injury because of a new shoe worn for too long.

Burn

Temperature and exposure time is the important causative factors. Long exposure time can cause burns on unprotected skin, e.g. resting close to the fire at night, resting the foot on a gearbox, standing in the hot sun on a metallic surface like a drainage cover.

Walking on an infected foot

Walking on a foot with an infected ulcer can change a simple, manageable situation into a serious problem. Only when the tissue damage has reached the deep tissues and the patient gets serious pain from the deep sensation may he/she seek help.

When a summary of these findings is made, the probable cause and ways to prevent recurrence will be defined.

LOCATION OF ULCER

Forefoot (3/4)

Tip of the toes: usually from claw toes, resulting in digging of the toe-tips into the ground.
Dorsum of the proximal interphalangeal joint: usually from a too tight shoe or a sandal straps.
Under a metatarsal head/the metatarso-phalangeal joint: mostly from repetitive moderate stress and a prominent metatarsal head from claw toe (intrinsic paralysis) deformity, collapse of the metatarsal arch and atrophy of the sole, often with callus formation of the skin.

In the instep

If not from a direct trauma, very often by a perforation from a tendovaginitis.

Hindfoot (1/4)

Fifth metatarsal base (1/8): usually in cases with insufficiency of the muscles innervated by the common peroneal nerve (foot drop or inversion). A 'high risk' ulcer, since infections in the fifth tarso-metatarsal joint easily spreads to the tarsal bones and joints, contributing to the deterioration of the tarsal bones (TD), with collapse of the longitudinal arch and instability of the foot resulting in a shift of the weight bearing to the central foot.

Heel (1/8): a heel ulcer easily causes destruction of the important heel pad, leaving a bad scar. The heel is difficult to resurface. It is almost impossible to compensate an insufficient heel with an orthopaedic device.

Examination of the foot

The examination of the foot will identify the cause, position, and type of an ulcer.
Observations: answers to the following questions will provide the answer how to manage ulcers.
Does the patient understand how ulcers are formed?
Does the lifestyle of the patient carry risk factors?
Is the profession a risk factor?
When did it start?
How did it start?
Any special event?
Has the patient's situation changed?
Any special reason for walking more than usual?
Is the patient wearing proper protective footwear acceptable to him/her?
Is there a total or partial loss of sensation?
Is there any clawing of the toes or foot drop?
Is there any stiffness in the joints?
Is there any inversion or eversion?
Has the metatarsal arch collapsed?
Has the longitudinal arch collapsed?
Is there hypermobility between the forefoot and the hindfoot (signs of tarsal disintegration)?
What is the likely cause of the ulcer?

TYPE OF ULCER

A simple classification is necessary, since the ulcers are usually examined by the field staff, who have to make the decision whether the patient can be treated in a peripheral setting, or must be sent to a centre for surgical treatment. Ulcers can be classified into two groups, *superficial* and *deep.*

Superficial ulcers involve epidermis, cutis and subcutis.
Deep ulcers involve any deeper tissues, e.g. fascia, bone, joint, tendon sheath, tendon.

PHYSICAL EXAMINATION

Thorough *physical* examination is essential for classification of an ulcer.

Palpation

- *Touching* reveals heat.
- *Pressing* gently reveals tenderness and discharge. A suspect joint may yield a drop of infected synovial fluid when pressed (osteoarthritis). Some drops of synovial fluid appearing on milking the tendon sheaths towards the ulcer indicates a tendovaginitis. Missing a tenovaginitis and not draining it can be disastrous.
- *Crepitations* can be felt when cartilage and bone are engaged.
- *Probing*: unfolding and flaming a paper clip can make a simple probe. Gentle probing gives information about depth and kind of tissue involved. Never use unsterile probes!

Measuring ulcer size

The approximate size of an ulcer can be registered by measuring with a divider and a scale. Monitoring should be carried out regularly during treatment.

Tarsal disintegration

Swelling of the ankle joint is very often a sign of tarsal disintegration (TD), a condition which very early leads to a total destruction of the foot, requiring amputation. TD is common in young people with sensory loss of one foot only. TD is a condition that requires urgent treatment by a specialist (leprosy surgeon or orthopaedic surgeon).

Heat swelling and fluctuation on the anterior or posterior side of the lower leg may be due to deep infection which has migrated upwards from the foot along the long extensor and flexor tendons.

Principles of treatment of plantar ulcers

PREVENTION

Self care training of the patient and family members

- Soaking and oiling
- Trimming

- Inspection for early signs of ulcer formation
- Ways of taking rest
- Basic dressing techniques for home use.

Stimulate formation of self-care groups for

- Sharing experience
- Mutual support.

Develop a footwear programme

- Protective footwear should be *acceptable* and *available*
- The programme should be *sustainable*
- The use of available commercial footwear, which can be modified, should be encouraged.

TREATMENT

- Immobilization
- Treatment of deep infection.

Treatment is surgical. Antibiotics should only be used if the patient's general condition requires it (septicaemia). Liberal, unnecessary use of antibiotics only creates resistance.

- Remove dead tissue by wide exploration and good drainage
- Restore weight bearing surface by careful planning of the intervention.

Almost all ulcers, even deep, will eventually heal by rest. They may reoccur early, though, if the cause of the ulcer has not been removed. Therefore it is necessary to analyse the cause of the ulcer carefully and remove the cause by change in lifestyle, proper footwear and surgery (aiming at upgrading the foot and preventing a new ulcer).

Necessary surgical procedures should be performed as close as possible to the patient's home and with nil, or as short as possible hospitalization.

TREATMENT BY WHOM?

Ulcer treatment should be differentiated into different levels and be performed by:

- *The patient or household member*
  Early on, the patient or a member of his household best takes care of minor ulcers, preferably after some self-care training.
  Self-care training can be provided by trained leprosy workers. The methods are rest, reduced weight bearing by sitting down, using crutches, cleaning the ulcer with clean water and soap, oiling the skin and covering the ulcer with clean cloth.

- *Local clinic should treat*
  Forefoot ulcers, requiring smaller interventions with no or local anaesthesia.

- *Peripheral hospital should treat*
  Forefoot and hindfoot ulcers, septic conditions requiring larger interventions in local or spinal anaesthesia, and requiring a short hospitalization.

- *Specialist hospital should treat*

  Forefoot and hindfoot ulcers, requiring larger interventions, including partial amputations, corrective osteotomies, and resurfacing of the sole. Gross deformities need surgical correction and a special orthotic device.

Early treatment as near as possible to the patient's home diminishes damage and development of disability, handicap and stigma and should be given high priority in leprosy programmes, vertical or integrated. The resources for such activities are usually already in existence. What are needed are proper planning, structuring and training.

Lepr Rev (1999) **70,** 70–77

Letters to the Editor

MULTIDRUG THERAPY

Editor,

Thank you for the editorial and commentary in the June 1998 issue of *Leprosy Review* regarding the new shortened multidrug therapy (MDT) regimen.

I think all of us working in the field of leprosy are agreed that the introduction of fixed duration MDT has been the single most significant development in the history of leprosy control and elimination. I am sure we also agree that the shorter the regimen can be the better, both for patient compliance and overall public health management. I do hope, however, that we would all hold equally to a commitment to proven treatment efficacy.

I was particularly interested that it was Dr Ji who wrote the editorial on this subject and was surprised by his contention that studies show a low rate of relapse. Dr Ji was co-author of the Institut Marchoux Study which appeared in the June 1995 issue of the International Leprosy Journal[1] in which he and the other authors conclude that: 'Relapses occurred late (at least 5 ± 2 years) after stopping MDT.' 'Relapse rate closely correlated with the bacterial load of the patient, occurring far more frequently among patients with a BI of ≥4·0 before MDT.' 'To avoid the alarmingly high relapse rate, it is proposed that the duration of MDT be doubled to 4 years in patients with an average BI of ≥4·0 before MDT.'

In this study, patients were analysed on two occasions with a gap of 2½ years (after 41·9 ± 12·1 months and 72·7 ± 17·3 months). It was found that in the intervening 2½ years, there had been a significant increase in the number of relapses. This led the authors of the study to a call for a 48-month regimen for high BI cases (while recognizing the operational difficulties). It is ironic that after a further 2½ years, one of the principal authors of that study is now arguing for a quartering of the regimen they proposed in 1995 (48 months to 12 months). It is also ironic that in both articles, Dr Ji refers to the WHO/CTD/LEP/94.1 document, which points to a low rate of relapse after MDT. In the most recent article, he uses the information as one of his main points for justifying 12 months MDT, whereas in the previous article we were being warned to interpret the findings of this document with 'great caution'.

Furthermore, in the June 1998 *Leprosy Review* article, we are advised that patients with a BI ≥4·0 are 'relatively scarce in the field'. In Nepal, where the bulk of patients are identified in the field and where there are generally no facilities for taking skin smears, it is not possible to say with certainty that the proportion of MB patients with BI ≥4·0 is low. Furthermore, nationally Nepal registers a far higher proportion of MB cases than in other countries. The Nepal Leprosy Trust in its centre at Lalgadh, Dhanusha District recorded almost one quarter of all the new Nepali cases registered during the 1997/98 fiscal year. The proportion of MB cases to PB cases was 60% to 40%, and of the MB cases registered, almost 10% had a BI ≥4·0. (This is 1 out of every 10 MB patients being put at an 'alarmingly high' risk of relapse.) On the basis of Dr Ji's comments regarding the overdiagnosis of MB leprosy, the actual percentage would be much higher.

On the basis of the 1995 article recommending longer chemotherapy for high BI cases and taking into account other factors, the Leprosy Control Division of His Majesty's Government Nepal agreed to shorten the regimen for MB–MDT to 12 months in the field, and that Referral Centres should continue

to offer 24 months MDT to patients with a confirmed BI $\geq 3{\cdot}0$ at start of treatment. This group accounted for 15% of MB cases registered last year at Lalgadh (not figures that could be described as being relatively scarce).

There is still no conclusive evidence to show that shortening regimens will not lead to higher rates of relapse. It is probably fair to say that even amongst the proponents of the new regimen, there is recognition of a possible increased risk of relapse. At the very least, therefore, it is not unreasonable to expect leprosy control programmes to address this issue actively. Shortening regimens without providing sufficient safety nets to those in danger of relapse seems both shortsighted and dangerous. Apart from the personal tragedy for those who do relapse, there is the negative impact of such an 'advertisement' on the control programme. In a programme like NLTs, where 65% of the 1500 new patients annually come as a result of recommendations from other patients, this is not an insignificant consideration.

I think the Nepal model of recognizing the risk to those with a high BI is a good one at the current time. I would propose one major development to this. Until such time as we can empirically prove that the shortened regimen does not significantly increase the risk of relapse, patients treated in the field where BI cannot be measured should be given 24 months MDT and only patients for whom a low BI can be confirmed (i.e. in a referral centre) should be given the shortened regimen.

Given the contents of Dr Ji's most recent article, I do not see any significant development in Dr Ji's information, only a different interpretation of the same data.

In the light of Dr Waters' commentary and in particular of his timely reminder that we are still a few years away from conclusive evidence that the relapse rates from the 12 months regimen will be minimal, I recommend we take a more measured approach to shortening regimens.

The year 2000 is our target, but elimination is the real goal. Let us ensure the year 2000 remains our slave, not our master.

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Reference

[1] Pierre Jamet, Baohong Ji and the Marchoux Chemetherapy Study Group. *Int J Lepr*, 1995; **63**: 195–201.

PROPOSAL REGARDING MB MDT

Editor,

Since the first sulphones were used in the 1940s, leprosy treatment has come a long way. In particular, the introduction of multidrug therapy (MDT) has been a success story. The factor missing in several countries in the 1980s was wide coverage in terms of percentage of patients treated with MDT. There is no doubt that the developments in leprosy treatment and the large reduction in global prevalence over the last 16 years are very exciting.

From the patient's point of view, perhaps the most exciting development has been progressive shortening of treatment due to the increased efficacy of MDT. Both patients and leprosy control programme managers would welcome even further reduction of treatment duration, as long as it has equal efficacy to the currently accepted global standard: 24-month fixed-duration MDT for multi-bacillary (MB) patients.

This is exactly the issue in the debate concerning the new 12-month MB MDT regimen recently recommended by the WHO. Along with many others, including Dr Patrick Lynch (see this issue), I am concerned that, while the efficacy of this regimen may be sufficient for some categories of MB patients, it would not be sufficient for others.

Dr Lynch draws attention to the Institut Marchoux Study,[1] which reported on the increased rate of relapse even with the previous 24-month regimen. We have also observed this after the introduction of the current 24-dose fixed-duration treatment. Before the introduction of clofazimine, the cumulative incidence of ENL was up to 25% in BL and 50% in LL patients. Thanks to clofazimine these percentages have now been more than halved. It is well known that such reactions can lead to irreversible nerve damage, blindness and other severe impairments.

The argument put forward in some WHO publications in favour of reducing the duration of MDT for all MB patients has been that highly smear positive (HSP) patients are nowadays rare. We have observed an increase in the risk of ENL reaction after the introduction of the current 24-dose fixed-duration treatment. There are three flaws to this argument. First, relapse from leprosy is not like relapse from other infectious diseases, such as amoebic dysentery or even malaria. Each leprosy relapse could spell social disaster for the person involved and also for their whole family. Second, the success of the MDT campaign is partly due to the trust that has been built up in the 'community', that leprosy can be cured. Often new cases present because they have heard that leprosy can be cured from others who have (had) the disease. An increased frequency of relapses could jeopardize this trust. Third, and most importantly, MB patients are most likely to relapse with multibacillary disease. It may take years in individual cases before the diagnosis of relapse is made. All the time they may be a source of infection in the community, creating a new pool of infection at a time when the battle against leprosy might otherwise have been in its final stage.

I contend that HSP leprosy is not rare in several of the currently most endemic countries. For example, in Nepal, where more than 50% of new cases are MB, the percentage of HSP cases has ranged from 7% to 40% in various large projects across the country. With case detection statistics of over 6000 per year, HSP cases cannot be called rare, even in absolute numbers. In our field programme in the Western Region of Nepal, 73% of the patients are classified 'MB'. Most (~80%) have a skin smear done at diagnosis. Out of 2346 new cases registered in recent years and who had a skin smear taken, 308 (13%) had an initial smear of >3+.

The figures published in the *Weekly Epidemiological Record* (WER) of 2 May 1997 (vol. 72, no. 18) also show that HSP patients are not rare. About 17% of 142,844 new MB cases reported in 1995 were HSP (BI >3+). If the data from India are considered separately, 25% of MB and 13% of all cases in the remaining countries had an initial BI of >3+. In many endemic countries the number of HSP patients is large enough to warrant our special concern. Table 3 in the quoted issue of the WER shows that in 1995, India registered an estimated number of 8842 new cases who were HSP, Brazil registered 5388, Indonesia 1507, Nepal 1374, Ethiopia 1329 and Madagascar 980. Because of the lack of (adequate) skin smear facilities in the field programmes in many of these countries, these figures may well be underestimates.

As stated by Waters in his editorial in the June issue of *Leprosy Review*,[2] 12 months of MB MDT is likely to be adequate for smear negative MB cases (or even for those whose smears are 1–2+). However, I am not aware of any current scientific evidence showing that 12 months of MDT has an equal or better treatment efficacy to the standard 24-month regimen for HSP MB cases. For this reason, it should be considered unethical to treat such patients with the shortened regimen.

Not many leprologists would recommend 12 months treatment to a patient if they knew the patient's skin smears were 4, 5 or 6+. The solution would seem easy: treat all HSP cases with 24-month MDT and all other MB cases with the 12-month regimen. One problem, however, is that in many field situations, smears are no longer done. Establishing reliable skin smear services has been notoriously difficult and with the advent of the 24-month fixed-duration regimen, many (including the WHO) no longer recommended that skin smears be done. All MB patients would receive the same treatment, regardless of their initial smear.

This means that in many field programmes, we no longer know who is (highly) smear positive and who is not. If the 12-month regimen is to be considered currently unethical for HSP patients, and I propose that it should, then it also becomes unethical to treat any MB patients with this regimen, as long as it is not possible to determine their bacteriological status. I therefore propose that we continue

treating all MB patients with a 24-month regimen, unless it is known that their initial highest BI is less than 3+.

Many countries have already implemented the new shortened regimen. Perhaps this was done without giving adequate consideration to the ethical issues involved. In such circumstances, I would recommend that the new treatment guidelines be modified as suggested above. An exception could perhaps be made for countries and areas where HSP patients are genuinely rare, say, less than 2% of the new cases.

It is accepted best practice in medicine only to implement a new treatment regimen after its efficacy and safety have been adequately demonstrated in scientifically conducted randomized controlled trials. Such trials would compare the efficacy and safety of the new treatment or regimen with the currently accepted treatment. According to Ji in his recent editorial in Leprosy Review,[3] such a trial is underway, testing the new 12-month MB MDT against the current 24-month regimen. Let us hope that in a few years time, after an adequate surveillance time has been completed, we will have evidence that MB MDT can be further shortened.

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References

[1] Jamet P, Ji B and the Marchoux Chemetherapy Study Group. *Int J Lepr*, 1995; **63:** 195–201.
[2] Ji B. Why multidrug therapy for multibacillary leprosy can be shortened to 12 months. *Lepr Rev*, 1998; **69:** 106–109.
[3] Waters M. Commentary. Is it safe to shorten multidrug therapy for lepromatous (LL and BL) leprosy to 12 months? *Lepr Rev*, 1998; **69**, 110–111.

LEPROSY BEFORE AND AFTER THE YEAR 2000: PRE- AND POST-ELIMINATION CONTROVERSIES NEED CLARIFICATIONS

Editor,

The subject of leprosy elimination by the end of this millennium is becoming a subject of controversy, mixed up with the post-elimination scenario. I would like to clarify some of the issues.

1. By definition, during the phase of elimination of leprosy, the endemic countries should be able to achieve a prevalence rate of less than one case per 10,000 population by the end of this millennium. WHO expects that countries endemic for leprosy should accelerate the leprosy elimination programmes within their countries. As a result of this momentum, countries should be able to reach the defined target at least at the national and in some cases at provincial levels. All the endemic countries may not achieve the elimination goal at district or sub-district or village level by the end of 2000 AD. Countries like China, Thailand, Maldives, Srilanka and many more who have achieved the prevalence goal are expected to monitor new case detection and treatment completion rate so as to also achieve lower prevalence levels. A simple method of monitoring designed by WHO, i.e. leprosy elimination monitoring (LEM), is a useful tool to the programme managers at various levels to identify shortcomings and improve their programme wherever necessary.

2. Leprosy elimination should not be confused with leprosy eradication, i.e. reaching zero new cases (incidence) of leprosy as with smallpox. As true incidence cases by definition are small, a large majority of new cases detected are hidden prevalent cases. Some leprosy elimination campaigns (LEC) have been promoted by WHO to clear backlog cases and bring them under MDT. If endemic countries have such campaigns at national level or sub-national level, detection rates show an increase which is sometimes misinterpreted as a rise in leprosy cases. Once this backlog is cleared, one might be able to define the true incidence. Until then, as we are dealing mostly with prevalence cases, it is proper to use registered prevalence rate (point prevalence) as a yardstick to declare leprosy elimination. However, a small

proportion of the population infected several years ago will show clinical disease resulting in occurrence of new cases (incidence cases) for many years to come. Some of them may present with MB leprosy. Some may even present with disabilities, where active search is not practised. No doubt, countries where case finding either through LEC or by other methods was not considered seriously may still continue to report a high detection rate with backlog cases in pockets even after reaching the goal of leprosy elimination. Of course, the programme managers should not go by the statistics received from the periphery reporting a declining trend of prevalence rate (this declining trend will be much faster in view of short duration treatment) without monitoring detection trends and revising the estimates from time to time. Otherwise, the elimination of leprosy will not be realistic.

3. The post-elimination issues arising out of immunological and neurological components of the disease, including post-MDT residual skin lesions, should not be considered as a yardstick to measure the success or otherwise of leprosy elimination. As a robust and simple technology is available to arrest disease transmission, priority has been accorded to case detection and treatment. Introduction of the MDT programme itself has reduced disabilities among new cases considerably, wherever active case search has been attempted. The WHO have estimated, that MDT may have prevented the occurrence of new disabilities to the extent of 50–98%.[1] Wherever possible, some attempts are being made to develop and implement disability prevention and care services with available resources, especially by NGOs in a patchy way. We may be dealing with 2–3 million leprosy disabled during the post-elimination or eradication phase. At this stage of the leprosy elimination campaign, these issues should not be mixed up with the arrest of disease transmission.

The immunological and neurological problems in leprosy are definitely major problems needing research to develop simple interventions. However, until simple tools are available for predicting reactions and neuritis to prevent disabilities, we have to aim at identifying new cases and provide MDT even in the most difficult areas and difficult population groups, to arrest disease transmission and reduce the incidence of disabilities.

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References

[1] World Health Organisation. Leprosy disabilities. Magnitude of the problem. Weekly Epidemiol Rec, 1995; **38:** 269–275.

INTRAOCULAR LENS IMPLANTATION FOR CATARACT FOLLOWING LEPROSY

Editor,

Cataract is the commonest cause of visual loss following leprosy,[1] which is fortunate as it is reversible by surgery. The recent congress in Beijing gave a chance for ophthalmologists to interact, and the following proposals are directed at this group and at programme managers. But first it should be stressed that eye doctors are not themselves the main actors in preventing visual loss, though their support is vital. The pillars of prevention are firstly prompt starting of MDT, and secondly training of front-line workers to detect, treat and refer complications before they become blinding.

However, even with good prevention, many people who have had leprosy will develop cataracts,

mostly just age-related cataracts like the general population, but some complicating uveitis. Nowadays, the standard of care for cataract has become intraocular lens (IOL) implantation even in resource-poor countries.[2] To date in leprosy patients, simple extraction and spectacle correction has been the norm.[3] It is time that they too routinely benefited from IOLs. A few doctors have been doing this for some years, but surprisingly it is only this year that the first reports have appeared.[4,5] These initial results are very encouraging even in high risk cases,[6] but even so caution is sensible. It seems that introduction of IOLs in tropical countries has often not been smooth, with far too many bad outcomes. This is partly because of lack of expertise and difficulty of follow-up, but there may also be racial differences (for example, the African eye appears to react more vigorously). To this now is added the leprosy factor, with many MB cases (and some PB) having had uveitis. Probably all MB cases have mycobacteria in the anterior uvea, often in large numbers and for long periods.[7] The use of IOLs following other forms of uveitis is now becoming widely accepted, but even so caution is needed despite the good initial results reported after leprosy.

In the coming decades, many of the millions now released from treatment will need the operation, so I think it is important that a careful audit/study should be done now to examine the outcome, and to be forewarned of any complications. I suggest that this should be done in different countries using the same protocol so that experience can be shared. The study should be done under the following conditions (which will involve substantial extra work):

1. Surgeons should have completed their learning curves and be getting consistent good results under field conditions.
2. Outcomes should be compared with a control group from the general population.
3. The database should be detailed, with pre- and postoperative features, and also details of the type, duration and treatment of the leprosy; this will enable the contribution of leprosy factors to be evaluated if complications occur.
4. There must be adequate follow-up of at least 1 year, which will necessitate home visits.

What do other ophthalmologists feel about this?

The other blinding complication which involves eye doctors is permanent lagophthalmos. Which operation should be done and when, is, however, quite unclear.[8] Some series with good results were presented in Beijing but the underlying uncertainty was not addressed. It is surely time that doctors who frequently operate for this got together and brought it also into the era of evidence-based care, though this is going to be more difficult than for cataract.

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References

[1] Waddell K, Saunderson P. Is leprosy blindness avoidable? *Br J Ophthalmol*, 1995; **79:** 250–256.
[2] Tielsch H. Editorial. Appropriate technology for cataract surgery. *Lancet*, 1988; **352:** 754–755.
[3] Girma T, Mengistu F, Hogeweg M. The pattern of cataract and postoperative outcome of cataract extraction in Ethiopian leprosy patients as compared to non-leprosy patients. *Lepr Rev* 1996; **67:** 318–324.
[4] Batistella G, Maakaroun M, de Castro A. Extracapsular cataract extraction and intraocular lens implantation in leprosy patients: visual outcome and complications. *Ind J Lepr*, 1998; **70:** 5–10.
[5] Anand S, Anand S, Babu G *et al.* Intraocular lens implantation in leprosy patients. Presented at 15th International Leprosy Congress, Beijing, 1998.
[6] Daniel E, Ebenezer G, Abraham S *et al.* Posterior chamber lens implantation in smear-positive leprosy patients; a preliminary report. *Int J Lepr*, 1997; **65:** 502–504.
[7] Job C, Ebenezer G, Thompson K *et al.* Pathology of the eye in leprosy. *Ind J Lepr*, 1998; **70:** 79–91.
[8] Courtright P, Lewallen S. Current concepts in the surgical management of lagophthalmos in leprosy. *Lepr Rev*, 1995; **66:** 220–223.

LEPROSY TERMINOLOGY IN NEPAL

Editor,

The recent International Leprosy Congress was a great opportunity for many of us to renew acquaintance and to update our knowledge and thinking about leprosy in the fight for 'a world without the problems associated with the disease – both medical and social' (Dr Yo Yuasa).

What to tell people just diagnosed with early leprosy about their condition was a subject discussed at the Congress. 'We must tell them they have leprosy – we must tell the truth!' was the strong opinion of a European working in Africa. Certainly we should 'tell the truth', but we must be very aware of what 'truth' we are telling. Dr Noordeen mentioned that in some languages there may be several words for leprosy. That is certainly the case in Nepal. The translation task would be simple if the words for '*leprosy*' used in the different languages each held the same constellation of meanings and cultural implications. However, this is not the case. Languages must be examined carefully before a word choice is made. A word should be used with full knowledge of what is actually being said.

Nepali holds three main words which can be translated by the English word '*leprosy*'. These are '*Kustha Rog*', '*Maha Rog*' and '*Kor*'. There are similar words in Indian and Asian languages.

'*Kustha Rog*' is a word meaning literally 'the disease of rotting flesh'. '*Kustha*' is an ancient term: 'According to Vagbhata (600 AD) the name ''*Kustha*'' was derived from ''*Kushnate*'' which means ''eating away'' in Sanskrit, and was mentioned in the Sushruta Samhita, written in India in about 600 BC'.[1] The term '*Kustha Rog*' therefore holds the concepts of disability and deformity, ulcerated hands and feet, 'having no hands and feet', incurability, a curse from the gods and implies the need for social separation.

'*Maha Rog*' is an old Nepali term which used to be used in official documents – the law previously made provision for compulsory isolation, with food, clothing and shelter provided.

'*Kor*' is best rendered by the English '*leper*' and contains the expectation of being a social outcast', of begging, of deformity; some go as far as to say that those who are '*Kori*' (one with '*Kor*') have a duty to commit suicide. The three words are to some extent used interchangeably by the general public in Nepal, with the term '*Kor*' frequently used as a term of abuse.

In Nepal, the word '*Kustha Rog*' is used to translate '*leprosy*'. It was introduced to the National Legal Code in the 1970s and is now used in official government documents to refer to '*leprosy*'. During my research, it became clear that the term '*Kustha Rog*' in Nepali has almost no commonality of meaning with what medical scientists mean by the term '*leprosy*'.

From a scientific biomedical perspective, particularly in reference to early cases, the word '*leprosy*' is used to mean a manifestation of skin and nerve signs and symptoms which may be a single particular kind of skin patch or nerve enlargement. Definitely no disability, deformity or social isolation is meant. When we tell a new patient that they have '*leprosy*' (rendered in Nepali) we are unfortunately actually saying, 'You have ''*Kustha Rog*''', with its association of physical deformity and broader socio–cultural implications.

There can be life-and-death consequences from using these terms in Nepali. While undertaking research I heard of patients who had attempted suicide in reaction to their diagnosis. A teenage girl hanged herself upon diagnosis and admission to the leprosy hospital. Another woman confided that she had been 'on her way to jump in the river' when she was encountered on the trail by the leprosy staff. By all means let us 'tell the truth', but let us be clear which 'truth' we are telling.

There is much more to share on this issue, but I will leave it there for now and ask if others have experiences and insights about telling the 'truth' to patients.

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Reference

[1] Thangaraj RH, Yawalkar SJ. *Leprosy for medical practitioners and paramedical workers*, 2nd revised edition. Ciba-Geigy Limited, Basle, Switzerland, 1987: p14

Lepr Rev (1999) **70,** 78–84

SPECIAL REPORT

INTERNATIONAL LEPROSY CONGRESS, BEIJING, 7–12 SEPTEMBER 1998. WORKSHOP REPORTS

Disease and disease control

Workshop 1–defining disease and antibacterial therapy

DEFINING DISEASE

The WHO definition for a case of leprosy is:

A person having one or more of the following features and who has yet to complete a full course of treatment:

- Hypopigmented or reddish skin lesion(s) with definite loss of sensation
- Involvement of peripheral nerves, as demonstrated by definite thickening with loss of sensation
- Skin smear positive for leprosy.

This definition is meant for public health purposes with respect to the required duration of treatment. However, a person affected by leprosy has several other medical needs consequent to *Mycobacterium leprae* infection. It was pointed out that a complete definition of leprosy would require inclusion of its bacterial, physical, disabling, interpersonal, social and cultural manifestations as well as its impact on women in many societies. Furthermore, cure involves more than the killing of bacteria and the disappearance of outward signs of active disease. The Group discussed these requirements extensively. Because creating such an all-inclusive definition would be difficult, a majority of the Group felt that the basic definition given by the WHO Expert Group is acceptable for operational purposes but is only a starting point for defining the needs of patients beyond the point of bacterial cure. Thus the Group strongly recommended that the programme (either a vertical programme or general health services) retain a registry of persons affected by leprosy since it will need to provide care to the patients, particularly with reference to reactions, neuritis, sensory impairment, iritis etc. and their consequences continuing or arising after treatment. Only in this way will the patient be reasonably assured of access to the necessary care in many programmes which are changing rapidly as prevalence decreases.

After completion of multi-drug therapy, it is expected that programmes will be capable of providing all the services required by leprosy patients to both treat and prevent further complications in addition to continuing to manage the public health component. Thus health services will have the primary responsibility, both to control transmission and to meet their social responsibility to provide medical relief and rehabilitation for the persons affected by leprosy.

ANTIBACTERIAL THERAPY

Antibacterial therapy was considered with respect to duration, safety, efficacy, acceptability, simplicity and cost. All six elements are felt to be important but efficacy was considered as the key factor. The Group further felt that if all other conditions were similar, shorter regimens are preferred. It was also

agreed that even beyond the year 2000, MDT should be made available in blister packs and cost factors should not limit the provision of good quality medicines.

It was agreed that if newer regimens become available with more or less equal efficacy but with a similar duration of therapy, there might be little advantage to changing from presently available and recommended WHO MDT.

It was stressed that results of clinical trials should be reported giving information on efficacy and issues related to side effects, reactions and neuritis. Efficacy decisions should be based on clinical and bacteriological improvement and more importantly taking into account relapses. When deciding on implementation of such newer regimens all the above elements should be considered. Furthermore, as regimens become shorter, the likelihood that complications of the disease will more frequently occur post-treatment may increase and if clofazamine is excluded from such regimens the frequency of ENL may rise. Planning for implementation of such regimens should also take these factors into consideration. The cost of such regimens must of course also be considered as well as operational factors.

Workshop 2–early case detection workshop

The members of the workshop discussed the issues related with detection, especially the role of active and passive case-finding and the need to make sure that all cases that are detected are able to complete treatment. The various reasons for wanting to detect cases early (to reduce transmission, to prevent disabilities and to monitor the effectiveness of the programme) was discussed and the members agreed that for operational and practical purposes the focus of this workshop will be on the role of early detection to prevention of disabilities. As such, the *definition* of early detection was defined as 'detecting a case of leprosy before disability sets in the hands, feet, eyes and face'. This means zero disability at the time of detection (based on WHO disability grading) without considering the time lag before diagnosis.

It was agreed that the present tests available for the diagnosis of a case of leprosy were not reliable and practicable for use in the field. There was also no practical and reliable way to measure the time lag between the onset of disease and diagnosis, except for asking the patient, which most of the participants felt was a subjective measure. The implications of single lesion and indeterminate leprosy in early case detection were discussed. The group discussed low sensitivity and specificity of the diagnosis of single lesion and indeterminate cases (considering that most of the programmes are classifying cases only as PB and MB cases). The possibility of some single lesion cases remaining undiagnosed for several years and the self-healing nature of these types was also highlighted for consideration. By definition, these will be included as early cases because they will not be having disabilities at the time of detection, but will not be used for monitoring purposes.

For *monitoring* early case detection, the group agreed to use the current WHO grading scale for disabilities and recommends to use the proportion of grade zero disabilities among new cases.

With regard to improving early case detection, the group felt that the following measures should be carried out as part of the routine activities in leprosy control programmes.

- To increase awareness about the disease at peripheral levels. This includes preparing different messages for different target groups taking into account rural urban differences, literacy rates and health seeking behaviour. The need to identify the most appropriate people to promote community awareness (apart from the health worker) was considered to be important.
- To integrate leprosy services into the primary health care system so that patients are treated nearer to their homes.
- To make diagnostic and treatment facilities attractive and easily accessible, and to provide good quality care to the patient including POD services.
- The group felt that active case-finding should not be stressed because of the costs, and most of the patients detected through such means are unlikely to accept the diagnosis.

- The group also felt that because of the social problems involved with active surveillance of contacts (need to identify index case), it should not be emphasized for early detection. Educating the patients to bring household contacts in a passive way should be encouraged.

With regard to sustaining early case detection under low endemic situations, the group felt that early case detection should be a goal regardless of the level of endemicity. The following measures were felt to be important in maintaining early detection under low endemic situation.

- Under low endemic situations the early case detection should be aimed to benefit the patient and not aimed at benefiting the community by cutting disease transmission.
- Maintaining public awareness about the disease will be crucial under such circumstances.
- Integration and strengthening the integration process will be the key measure to sustain early detection.
- Training of general health workers for early diagnosis will be important and referral facilities should be made available at a suitable level to ensure that necessary expertise exists to deal with certain diagnostic problems which the general health services may not be able to tackle.
- Leprosy should also be included in the management of common skin diseases at the peripheral levels for which collaboration with the dermatological services is needed, i.e. training.

Workshop 3–organization of leprosy services under low endemic conditions

WHAT IS MEANT BY LOW ENDEMIC CONDITIONS?

We looked at three possible indicators of low endemicity, namely: case detection rate, registered prevalence and prevalence of disability. The workshop felt that case detection rate (CDR) would be the most appropriate measure to use, as that indicates the actual number of patients requiring services and it also drives the other two indicators. A CDR equivalent to a registered prevalence of 1 in 10,000 is about 5 per 100,000, so we took a low endemic situation to be one with fewer than five new cases detected per 100,000 population per year. It was noted that the geographical distribution is such that many countries will have areas of very low endemicity and other areas with more patients (e.g. China, where the overall CDR is very low, but most leprosy occurs in three provinces).

The prevalence of disability may be the significant statistic in describing the leprosy workload in any area: the residue of disability is the major problem for the next millenium.

CASE DETECTION

Even in rich, low-endemic countries, leprosy patients often remain undiagnosed for a long time (4–6 years); it seems likely that as endemicity decreases, the average delay in diagnosis will increase. In richer countries, leprosy patients are referred to dermatologists. For poorer countries with a low endemicity, there will be a need to dismantle the vertical leprosy programmes and change to a policy of suspicion at the peripheral level and referral to a specialized level for diagnosis and management of complications. The private and traditional sectors must also be involved in referring suspects.

TREATMENT

Accessibility is the main issue, with many patients living a long way from leprosy expertise. The provision of MDT could be linked to other programmes such as TB. Peripheral clinics could hold blister-packs for leprosy, according to the numbers treated in the previous year. For very distant patients, treatment can be given for 3–6 months at a time.

MANAGEMENT OF REACTIONS

Reactions are possible at any time in the 5 years or so after diagnosis. After discussion, it was felt that in low endemic situations in poor countries, it would not be possible to provide expertise in nerve function assessment at the peripheral level. As most patients would not be able to go regularly to the referral centre, there must be a much improved methodology for educating patients to recognize symptoms of reactions and neuritis and voluntarily report for appropriate treatment. Such a system could involve former leprosy patients. The same person who is trained to diagnose leprosy should be trained to manage reactions and neuritis, and prescribe steroids.

PREVENTION AND MANAGEMENT OF DISABILITIES

The example of self-care groups in Ethiopia was mentioned, with the leprosy patients' associations potentially playing an important role in helping so support those groups and assist in the provision of rehabilitation services (both physical, social and economic). Stigma was discussed, with the feeling that it may perhaps increase in some situations as the endemicity decreases.

In addition to patients' associations, other organizations (e.g. NGOs, government welfare departments, etc.) should be involved in providing basic services such as protective footwear.

COSTS

While there may be many cost savings in an integrated setting, some additional costs must be considered, especially those affecting patients, such as the costs involved in more visits to a referral centre, which may be some way away. Payment for items such as footwear is also likely to be required.

While savings may be made, it is likely that the quality of the case management of individual patients will decrease in this situation.

URBAN AND RURAL AREAS

While leprosy patients will face different problems in these different settings, it was felt that most are not specific to leprosy; leprosy patients will be similar to other patients in this respect and they will be helped by strengthening the basic health services and the referral system already in place.

MONITORING

The major problem in monitoring is usually that too much information is collected. In this situation, it was felt that a minimum of information should be routinely reported and any further information requirements would be met by appropriate surveys. The minimum data required are: the number of new cases, the number completing treatment and the number of new cases with grade 2 impairment.

TRAINING REQUIREMENTS

Training is required at the peripheral level for suspicion and referral. This has been developed in the field of dermatology, especially in Tanzania. The idea is that the peripheral worker would be trained to identify and treat up to five or six locally important skin conditions; other skin problems would be referred. This worker would not be taught anything specifically about leprosy, except to be able to give out MDT to known leprosy patients.

At the diagnostic level (often at district level), a health worker (nurse, medical assistant or doctor) would be trained to diagnose leprosy and manage the common complications, including reactions and neuritis. This person would also be trained to handle other health problems (either general, or perhaps another related field, such as dermatology or TB). In Tanzania, these staff are trained for 2 years in

dermatology, STDs and leprosy, as well as programme management. In some other countries in Africa, district TB/leprosy officers are trained for just 4–6 weeks. Each country would have to determine who, where and for how long such staff would be trained.

Tertiary referral should be possible in every country, where all disabled people (including leprosy patients) can receive appropriate treatment.

Workshop 4–prevention of disability

PLACE OF PREVENTION OF IMPAIRMENT AND DISABILITY (POID) IN LEPROSY CONTROL

Prevention of impairment and disability is integral to leprosy. From the perspective of the patient, impairments and disabilities constitute the essence of the disease. Thus POID should be integral to any leprosy control programme, be it vertical, integrated or otherwise organized. It is understood that early detection and the provision of MDT are the primary means of POID. Yet nerve impairment and resulting disability remain a vital issue in many cases, and need to be addressed at every level. This means that POID activities should be defined, implemented, and recorded effectively. Evaluation should occur using appropriate parameters, adequate teaching material provided, and sufficient resources supplied.

CONCEPTUAL FRAMEWORK AND COMMON LANGUAGE

A comprehensive concept of POID needs to be developed involving all areas of leprosy control, including early detection, provision of MDT, nerve assessments, prevention of nerve function impairment, reconstructive surgery, rehabilitation, and the socio-economic situation of the patient. It is recommended that a common language is adhered to, based on the new ICIDH-2 (WHO International Classification of Impairment Disability and Handicap).

POID AT THE START OF, AND DURING CHEMOTHERAPY

Nerve function assessments should be performed and recorded adequately. It is acknowledged that the technical level of assessment may vary per region or country. The aim is to prevent (further) deterioration of nerve function. Motivation and personal attention by health care staff is essential. A mechanical test is of limited value if it is not followed by appropriate action. Impairment grading should be done before starting, and after completing chemotherapy. Reporting formats should ask for this information to be recorded. Field control cards in particular should be appropriate to POID.

Recent nerve function impairment and reactions should be treated with corticosteroids whenever possible. If the structure of a programme permits, and quality conditions are met, the provision of corticosteroids can be given at field level. Otherwise a referral system needs to be in place.

Health education, training of medical staff at all levels, and provision of sufficient resources are essential for the success of POID.

Referral options for specialist POID care are imperative to make an integrated leprosy control system work.

POID AFTER CHEMOTHERAPY

In addition to comments made above, the following points were made:

Patients need to receive adequate health education so that they are empowered to understand when and where to request care if complications due to leprosy arise after they are released from treatment with chemotherapy.

For high risk patients (e.g. those with initial high bacterial load), it is recommended to organize adequate follow-up after completing chemotherapy in order to recognize and treat nerve function impairment and leprosy reactions in time.

MANAGEMENT OF PEOPLE WITH ESTABLISHED NERVE FUNCTION IMPAIRMENT AND/OR DISABILITY

People with lasting complications due to leprosy in the form of eye problems, ulcers, muscle paralysis, etc. should receive continued care. This is preferably provided at community level (community based rehabilitation), but referral for specialist care should also be available.

ALLIANCES AND PARTNERSHIPS

It is preferable that people with secondary complications due to leprosy are treated in general medical facilities whenever possible. Eye problems, for instance, can usually be dealt with adequately in general eye units or services.

Reverse integration is also possible, where leprosy treatment centres provide specialist care for non-leprosy patients. Examples of this principle are ulcer care for diabetic patients, and hand therapy for trauma victims.

Education about leprosy and leprosy complications should filter into general medical services at all levels in order to facilitate integration and partnerships.

Summary

Four workshops were conducted during the congress under the disease and disease control theme. The workshops were on the issues of defining disease and antibacterial therapy, early case detection, sustaining leprosy control in low endemic situations, and the prevention of disability. These workshops spanned the spectrum of disease and its consequences through from early detection, the definition of disease to the prevention of disability. All of these topics being important contemporary issues challenging leprosy control programmes world wide. Despite the broad spectrum of the topics it was interesting to see that a number of important themes emerged which were common to all topics. It is possible to identify five major themes arising from the output of the workshops which are now described below.

Each of the workshops adopted broad and comprehensive approaches to their topic. In the past, there has been narrowness in defining disease in terms of the need for chemotherapy. The approach taken in the workshop now is for a much more comprehensive approach looking at all the consequences of the disease process rather than the requirement for antibacterial chemotherapy. Similarly broad approaches were taken to low endemic situations, considering comprehensive approaches which are inclusive rather than exclusive. Disability prevention also continues this same theme of comprehensive approaches based on multidisciplinary involvement in prevention of the consequences of the disease process.

The second major theme to be identified in the output of the workshops was the importance of relevance to patients and people affected by leprosy. It is no longer adequate to view programmes in terms of their acceptance to those running the programmes. Control programmes must be acceptable to the people they are designed to benefit. This even impacts on definitions of disease in terms of what matters to patients rather than only restricting this to disease pathology. Similarly, approaches to disability prevention are not merely about measurement of impairments due to nerve function deficit but rather consider the abilities and functions which are most important to the individuals affected.

The third theme which spans all of the workshops is the need to develop partnerships with others in addressing the challenges of leprosy today. Each workshop identified important groups with which partnerships need to be developed included local patient groups, voluntary associations and primary health care services. All of these have a role to play, from early case detection right through to the prevention of disability and the sustaining of control under low endemic situations.

The fourth important theme is sustainability of programmes which need to be developed for the long term benefit of those affected by disease rather than short term goals. Again, this impacts an area such as

case detection methods which need to be sustained in the long term. Approaches such as intensive case detection through mass survey are not sustainable given changes to the patterns of disease, whereas involvement of communities and community participation in the process of early case detection is a much more sustainable approach. This is important, as programmes attain low endemic status and is also important in preventing disabilities where the progressive nature of secondary impairments following primary impairments may be lifelong.

The final theme is that of the importance of training, as each area is recommending new approaches to be taken and for new people to be involved in leprosy programmes. The implications are that those to be involved need to be trained and that the training requirements will be different from those of the last ten years. Training programmes will need to adapt to a wider range of individuals and groups being involved in programmes and to much more comprehensive approaches. These implications for training are profound and training centres and training programmes rapidly need to adapt to this changing situation.

These key themes emerging across the four workshops on disease and disease control are significant. They have major implications for leprosy control programmes over the next 10 years.

W. CAIRNS S. SMITH (Moderator)

Lepr Rev (1999) **70,** 85–94

Social aspects and rehabilitation

Workshop 1—people affected by leprosy as working partners

'To get rid of the stigma, we have to have self-confidence first'

Cheng-Li Wang, China

'We used to say that if society changes, we will be able to change. But we should not rely on this. We should discard this attitude and adopt the belief that society will change because We Ourselves Change. Let us believe this and make our lives rich and rewarding ones'

Miyoji Morimoto, Japan

'People affected by Hansen's disease do not need charity, but the opportunity to show we are capable, and in so doing perhaps change the world'

Christiano Torres, Brazil

In order to achieve a world without leprosy, it is essential to harness the invaluable resource which is represented by persons affected by leprosy. We must all work together as partners in this global effort. Promotion of a positive self image and the projection of a positive image in society is at the core of the issue.

To this end, the use of non-labelling, non-stigmatizing language is of primary importance. Labels such as PALs, victims and sufferers must be avoided.

In some countries work has been initiated to address the social and economic aspects of leprosy and some organizations have made this a priority. However, much, much more needs to be done.

We have identified the following areas for action:

- Guidelines for appropriate terminology are needed.
- Self-confidence among persons affected by leprosy needs to be promoted.
- Discriminatory legislation and practices continue in many areas and present barriers to full participation.
- Every individual affected by leprosy has the right to information, both about the disease and treatment, and regarding available social and psychological support.
- People involved in leprosy-related work need to develop a greater level of commitment to working in partnership with persons affected by leprosy.
- Information and understanding on the part of the general public and health workers needs to be increased.
- Stigma and prejudice are still major problems in many countries and are often perpetuated by the media and fundraisers. It is important to work with people affected by leprosy to analyse and identify factors that influence the level of stigma. This will enable the

development of appropriate strategies to correct misunderstanding about the disease and misconceptions about those individuals affected by it.

- In many countries, there is need to change the attitude of health workers. Poor communication skills are a major problem which adds to stigmatization, low self esteem and hopelessness. Discriminatory attitudes of health personnel also need to be addressed.
- Attention to potential social and psychological problems is paramount. Training curricula of schools and universities should also include social and psychological aspects.
- Opportunities for self-expression are important for others to see that a person is more than his or her disease.
- The potential for self-stigmatization is high, even amongst persons with no visible disabilities, if support is not available.
- Attention to psycho-social issues by WHO and other influential organisations is of great importance.

RECOMMENDATIONS

1. Guidelines for appropriate terminology, taking into consideration cultural differences, should be developed with input from people affected by leprosy. These guidelines should be published and distributed.
2. Socio-economic improvement of persons affected by leprosy results in increased self-confidence and prevents marginalization. Skills development training and loan schemes aid in empowerment and in ensuring that individuals lead productive lives with dignity as fully participating members of the community.
3. An inventory of discriminatory legislation and practices throughout the world should be compiled. Individuals and associations of people affected by leprosy should be mobilized and unite with others for the repeal of these laws and discriminatory practices.
4. Information materials should be developed with input from persons affected by leprosy that address both medical concerns and social and psychological needs.
5. Creative strategies should be developed that will renew the commitment of policy makers to issues related to leprosy.
6. Stigma related factors should be researched and analysed to develop appropriate health education strategies and define specific messages. Full use of the media should be made and societies of professional journalists and the media in general need to be pushed to keep issues related to leprosy on the agenda,
7. Health education about leprosy for the general public and health workers should be intensified in order to prevent the distribution of erroneous information.
8. Training in communication skills should be required for every health care worker.
9. Curricula of schools and universities should include socio-psychological aspects of leprosy.
10. Writings, music, art and other forms of self-expression by people affected by leprosy should be encouraged and utilized to create a positive image.
11. People affected by leprosy with potential leadership skills should be identified to participate in self advocacy workshops. This will promote the creation of self-help support groups. In this way, individuals will be empowered to assist each other cope with feelings of fear, insecurity and hopelessness. This, in turn, will result in people who can effectively educate the public.
12. Efforts should be made to include leprosy-related issues on the agendas of meetings outside the scope of leprosy.

13. WHO and other influential organizations should create advisory boards which include people affected by leprosy to help in the formulation and implementation of policies directed at the elimination of prejudice and discrimination associated with leprosy.

'We want to be a part of the process, to be in a position to help others as well as ourselves. It is our desire that our participation will be accepted as a giant leap forward towards the development of an international partnership aimed not only at the elimination of Hansen's disease from the face of the earth, but also at reaffirming the humanity of all persons affected by Hansen's disease. A Quest for Dignity'

Bernard Kawaka 'Okalani Punikai'a, Hawaii, USA

Workshop 2—social and economic integration

The social and economic integration of persons affected by leprosy as an important means for promoting human dignity, reducing stigma, increasing economic independence and efficiently using limited community resources.

The level of integration achieved by people affected by leprosy differs widely around the world. While much progress has been made in integrating the medical care of people affected by Hansen's disease into the general health care systems of their countries, less progress has been made in integrating them into established community based socio-economic support systems.

One possible reason for this is that the development of socio-economic support programmes fall outside the missions of the Ministries of Health and of the WHO which coordinate the medical aspects of Hansen's disease work. In recent years, almost total concentration has been on the delivery of MDT in order to achieve public health goals. Another reason is the complexity of the socio-economic problems that need to be addressed for true integration to occur. Thirdly, most non-governmental organizations which have a strong leprosy focus have few professionals at headquarters level or in the field with much training and experience in socio-economic integration. Fourthly, there is little contact and cooperation between Hansen's disease organizations and those international, national and local government and non-governmental organizations which do have expertise and programmes. And finally, of course, there are the problems of limited resources, remaining stigma and satisfaction with the status quo.

Considering the above situation, the Workshop on Social Integration recommends:

1. That the social and economic integration and empowerment of persons affected by leprosy become a priority for leprosy programme planners along with cure and prevention of disabilities.
2. That attempts be made by leprosy focused organizations and divisions to actively involve other appropriate UN agencies, government ministries, international, national and local NGOs with expertise and programmes in social and economic matters in the search for integrated, affective and efficient solutions to the medical and non-medical problems of persons affected by leprosy.
3. That persons with practical experience and training in socio-economic issues be designated within NGOs with a focus on Hansen's disease to promote access to and creation of integrated, efficient and effective programmes at the national and local levels for education, vocational training and placement, small business development, care for

the severely disabled and destitute, housing, transportation and other important socio-economic needs.

4. That these socio-economic 'experts' have regular meetings under the auspices of ILEP at the international and national levels to share information about successful programmes and to interact with 'experts' in organizations from inside and outside the leprosy world on subjects of mutual interest.
5. That in project areas, surveys be made of the socio-economic needs of people affected by Hansen's disease and of individual, local and national resources for solving these in an integrated manner. The aim of such surveys is efficient and effective action to resolve them.
6. That people affected by leprosy be empowered to develop solutions to their problems in partnership with other community members.

The committee also warned against the following dangers:

1. Failure to consider socio-economic implications of medical decisions (for example, long internment for treatment, surgery, rehabilitation or research, causing institutionalization).
2. Goal confusion. Who is the primary beneficiary of a proposed programme? The institution or individuals affected by Hansen's disease? At times people affected by the disease are kept in an institution because they are more needed to guarantee the success of an institution's programme than because of their own needs.
3. Isolating people affected by Hansen's disease by establishing socio-economic programmes in former leprosy institutions rather than in the community.
4. Excessive paternalism: sometimes for aged and severely disabled, paternalism is needed. For others it can be deadly to the spirit and should be avoided. In some countries people affected by leprosy have more special privileges (pensions, housing, transportation, etc.) than people with similar problems. This can create resentment and segregation.
5. Exploitation: lack of fair payments for work performed by people affected by the disease. Also excessive exploitation of the leprosy image to bring in donations. This harms normalization.
6. Inadequate solutions for individuals. People are different. Some do better employed, some in setting up their own small business, some in cooperatives, others in sheltered workshops and others because of age and disability should be taken care of.
7. Not actively involving persons affected by leprosy and their families in the process of solving their medical and socio-economic problems.
8. Not considering other needs besides employment: what about transportation, day care, housing, aids for the disabled, all of which make employment possible?
9. Sustainability: creating non-viable programmes. How will the individual or the programme continue after the initial grant has dried up? There has to be a regular flow of cash return. That requires products that people want to buy with fair pricing and a fair profit margin. It means carefully calculating costs and returns before setting up a programme.
10. Evaluation. Programmes needs to be carefully and honestly evaluated in relation to clear, established objectives.

Workshop 3—changing community perceptions and ensuring community involvement

The Conference organizers had given the workshop four key phrases: changing community attitudes, community involvement, use of mass media and community action.

CHANGING COMMUNITY ATTITUDES

1. Opening the discussion, one of the PALs mentioned that change in the perception of PAL ought to be the first step in changing community attitudes. To quote 'when I was informed of my diagnosis as a leprosy patient, it was almost a declaration of a death sentence by a doctor. This was further endorsed by the priest when this was related to the sins in my earlier life. This was a real trauma and the beginning of a psychological battle.' If one has to overcome this factor, apart from building the psychological confidence of PAL, it is essential to orient religious leaders and others around the PAL in his family or community so that they understand the real and scientific nature of the disease. This process of demystifying the disease of leprosy must begin simultaneously with the clinical diagnosis of the case. This can be further supported by strengthening and modifying the attitudes of the family, peers, and the community so that PAL is reassured of his continued status in his community.
2. Empowerment of PAL. Discussing empowerment, the workshop believed that empowerment means enabling PAL to fully utilize all his rights—political, social and economic—like any other citizen. Empowerment also means provision of opportunities for upgrading the quality of life like any other citizen and to fully accomplish the developmental potential. There are positive and negative aspects of empowerment. There are laws, regulations and conditions that create obstacles and constraints in the process of empowerment. For example, right to education, communication, marriage, property or voting are all fundamental rights. Denial of any of them would spell denial of human rights. To overcome these negative factors, a special effort will have to be made so that the empowerment process is not hindered. To convert the negative factors into positive, involvement of the community and media will be very essential, but ultimately the goal will be equalization of developmental opportunities.
3. The Community Based Information and Education Campaign as thought of as the best method to provide education and enlightenment to community at large and to PALs in particular regarding the disease and its treatment, and also regarding the rights and responsibilities of PALs. It was felt that such a campaign should be organized at the local, state, and national level with a partnership between PAL, NGOs, and governments. The media support for such a campaign, along with non-governmental service organizations may go a long way to provide follow-up and sustainability to the campaign.
4. Media has a significant role in demolition of stigma. Narration of experiences from various countries indicated that many times electronic and press media does not have up-dated and scientific information on leprosy with the result that the image created is a stereotype resulting in social stigma. This may be unintentional but the fact remains that many meaningful efforts will have to be made to change and restructure the image of leprosy in the print and electronic media. The first step will be to evolve a media strategy. It was suggested that WHO may play a leading role along with country governments so that country-specific media strategy is developed. This strategy will answer what product we want to market, how we want to market, what is our audience, and what is our focus. The Workshop felt that the next step will be to develop orientation programmes for print and electronic communicators at the district level, rather than the national level so that feature writers, editors of Sunday editions, and producers of TV and radio documentaries can create the correct image. The third step would be to develop a data bank on leprosy and a collection of stories with human warmth and photographs that may be attractive to the press. Religious, socio-economic leaders and cult figures may be encouraged to undertake

an advocacy role on behalf of leprosy. For this campaign, use of folk lore, folk arts, and theatre may be very useful to suit the cultural context. It was discussed whether the negative image was created because of disability and disfigurement resulting in the stigma. The workshop, however, thought that the positive aspects expressed in the declining numbers of disability and lowering of percentages of active cases and disfigurement may be highlighted to create a positive image.

5. There was an extensive discussion on stigma. Stigma was defined as a social response on a continuum beginning from total rejection to total acceptance expressed in the form of social distance. Measurement of social distance and quantification of stigma are new researchable areas in the social sciences. It was felt by the participants that when stigma is overcome, it can serve as a positive element in the battle against leprosy.

COMMUNITY INVOLVEMENT

The members felt that the majority of the PALs in developing countries belong to agricultural rural communities. In these communities family either nuclear or extended and the self-contained society provide a safety net and security. If one is able to utilize this safety net, it can be an effective instrument in prevention, identification, treatment and rehabilitation, ultimately leading to community based rehabilitation. The bonds in rural society are strong and if appropriately used, the entire community could be involved in preventing dehabilitation of PAL. It was also pointed out that while the leprosy problem, looks very large globally, if it is seen as a community problem at the village level, it is likely to be manageable. The additional advantage is of using the traditional institutions, such as a church, Sunday school, or village panchayat. Discussing this issue further, it was felt that the level of the village there is a definite change in the role of the health worker. This change from a provider to a facilitator, or from provider to health educator and counsellor is an important change in our battle against leprosy, but to achieve this we will have to provide technical support to the community leaders who have their roots in the village itself. With the electronic revolution, the supply of information may not be the problem. The problem may be of selecting the right package for the right worker.

USE OF MASS MEDIA

While mass media is enlarging its scope to cover the rural and urban communities, it is struggling hard to cope with demands that are made on the limited space, either on the page or on the screen, or on the air time. Naturally leprosy will have to compete with many developmental priorities. While communicators are ready to help, efforts on the side of NGOs, governments, and WHO are also necessary. It was pointed out that a recent survey has indicated that the international press releases are either full of statistics or are diluted statements. The government communication are highly politicized. What is needed is a copy which is scientific, true and attractive to the reader to catch his attention. For this purpose, we have to use the three steps mentioned earlier about media strategy, orientation and data banks.

COMMUNITY ACTION

It was thought by the Workshop that community action is primarily in the area of decision-making. These decisions pertain to the future of PAL. This may be in the field of economics,

politics, or the social structures. For giving them the opportunity to make decisions, empowerment of the PAL is a prerequisite. The community participation or action is going to depend on awareness of the people. The workshop believed that awareness is not merely registering the information, but is critical awareness leading to social action. With a change of role of community health workers, they need to be oriented in basic skills of community organisation, counselling and communications. For this, support will have to be given to develop and disseminate a simple manual along with training modules for community participation and organization. Such manuals will have to be field tested before they are used for community involvement. It was also mentioned by the workshop that community action will also mean networking, not only at the local level but also at the national level. This networking need not be restricted only to organizations working in the field of leprosy or health, but the networking could include all developmental organizations such as the National Council of Women, Council of Child Welfare, Social Security Association, etc. Such a network would help develop interpolation of ideas and help strengthen a common front against leprosy.

Workshop 4—global needs and opportunities for rehabilitation

The Workshop made the following recommendations:

ESTIMATING THE GLOBAL NEED FOR REHABILITATION

1. A conceptual framework needs to be adopted by those involved in rehabilitation in the field of leprosy. The workshop recommends that the WHO International Classification of Impairments, Activities (Disabilities) and Participation (Handicaps), draft 2 (ISIDH-2) should be adopted for this purpose. This would facilitate communication and building alliances with those working in other areas of rehabilitation.
2. To assess the needs at the different levels of impairment, activity and participation, and to monitor and evaluate interventions at these levels, additional tools and indicators are needed. The workshop recommends that as far as possible existing tools should be used or adapted for use with leprosy-affected people. Examples: for impairment grading the WHO grading system, for ADL the questionnaire from the WHO disability training manual and for participation/handicap the grading developed by Dr P. K. Gopal or the assessment developed by Sr. Senkenesh in Ethiopia.
3. The Workshop recommends that a workshop should be convened in the near future to look at what tools are currently available (see 2), how they could be used or adapted for use in leprosy, and to make recommendations for their use. This should be done in coordination with the GLRA-organized workshop on socio-economic rehabilitation in May 1999.
4. The workshop recommends that a special study should be done in selected areas to devise a more accurate method to estimate the global needs in relation to rehabilitation.
5. The workshop recommends that a cohort-based system of assessment and reporting of impairment status of people registered in leprosy programmes should be urgently introduced. This should be included in the appropriate reporting formats of the WHO and ILEP. The aims are quality assessment of programmes and collection of data for advocacy purposes.

6. It should be recognized that people with impairments (even deformities) are not necessarily in need of rehabilitation. Rehabilitation should address problems in activities of daily living and social participation. People who do not experience problems in these areas may happily live with their impairments. However, many would still need to continue to prevent their impairments from getting worse. They need to learn how to do this and may be in need of certain protective devices.
7. Needs assessment should incorporate or be targeted at providing solutions. Interventions should follow such assessments. This is also the WHO approach to CBR. Community workers are trained in problem solving rather than in standard techniques for particular disabilities. Needs assessment should therefore not be done in a vacuum, but should take into account the resources (potentially) available for rehabilitation interventions in a given area. The workshop therefore recommends that detailed needs assessments, such as surveys should be undertaken in not too large, well-defined areas, where rehabilitation services can subsequently be offered or facilitated.
8. The one to define the (nature of the) need for rehabilitation should be the affected person him/herself. Experience has shown that the most successful rehabilitation programmes are those where people assess their own needs. A study in Ethiopia found that of people affected by leprosy only 20% identified themselves as needing rehabilitation. The workshop noted the need to raise awareness of rehabilitation opportunities among the target population, so that they could take well-informed decisions about their needs. Reaching those most in need may be the most difficult, for reasons such as lack of motivation.
9. Rehabilitation requires a process of understanding, which may need a process of growth in the affected people, before they are ready to participate. Motivation by (good) example is a powerful tool in this context. People who have initially rejected rehabilitation should also be given a chance to change their minds.
10. From the point of view of the affected person, their needs are physical, social, mental and spiritual. Our rehabilitation approach should therefore be holistic instead of compartmentalized.

IMPLEMENTATION OF REHABILITATION

1. Governments and organizations need to be stimulated/motivated at different levels to promote rehabilitation. This should be done with a multisectoral approach. Possibilities include the setting up of a multisectoral steering committee at the national level (e.g. Ethiopia) or decentralizing to more peripheral development programmes (e.g. Sri Lanka). In the experience of AIFO, achieving this at the district or provincial level is easier than at the national level. Each country or project needs to see which approach would be the most appropriate/effective in their situation.
2. The workshop noted the problem that people affected by leprosy needing rehabilitation are often spread out over a large geographical area. Modified CBR approaches may therefore be needed to address their needs.
3. Where services or infrastructure for leprosy work are established, there is a great potential for 'reverse integration' in relation to rehabilitation. General CBR services could be set up around existing leprosy services.
4. The workshop emphasized the importance of referral and support systems for rehabilitation without which CBR programmes cannot function. A network of available rehabilitation and referral facilities should be created.

5 Centres like ALERT could function as regional focal points for training and collection of experience and information and could serve as resource centres on rehabilitation.
6. The workshop recommends that leprosy workers should take advantage of documents such as 'The Standard Rules for Equalization of Opportunities for Persons with Disabilities' by the UN (1994). These should be studied to see how they would apply in the national or local situation, regarding people affected by leprosy.
7. Rehabilitation projects and proposals should be made gender sensitive. Women should be included as staff and volunteers, ideally proportional to the percentage of women needing rehabilitation.
8. The workshop stressed the importance of marketing awareness and research in relation to vocational rehabilitation. The expertise present in other organizations should be tapped.

Summary

MAJOR ISSUES

1. Equal rights and opportunities for people affected with leprosy to develop their full potentials is a matter of human rights.
2. Leprosy and its consequences are a complex human problem leading to discriminations, stigma and prejudices.
3. There is lack of complete understanding about global needs for rehabilitation.
4. Concentration on medical care of people affected with leprosy (MDT, surgery, etc.), though vastly beneficial, has led to highly inadequate psycho-socio-economic rehabilitation in a holistic manner resulting in poor quality of life.
5. People affected with leprosy have not been full partners and decision makers for their own development and lack self-confidence and opportunities for self-expression.
6. Community and health providers lack the right attitude and sensitivity, thus failing to assist in the empowerment of people affected with leprosy in an integrated manner.
8. There is insufficient coordination at international/NGOs/government levels to utilize scarce resources to allow full development of people affected with leprosy.

RECOMMENDATIONS

1. Estimation of global needs: using existing tools with necessary modifications, need assessment and relevant interventions in rehabilitation at global/national/field levels requires urgent attention to enable all concerned to take specific actions recognizing that not all require rehabilitation.
2. Change in perceptions and attitudes: using mass media and other tools like training, counselling, etc., changes in behaviour resulting in positive attitudes of communities, patients, their families and health providers are of paramount importance to ensure social amalgamation and reduction of stigma/prejudices.
3. Empowerment: provide information, education skills, resources and motivate people affected with leprosy to empower them to lead a dignified, self-reliant quality of life and achieve their full potential with access to equal opportunities.
4. Community based rehabilitation: CBR with modifications is appropriate in most of developing countries to provide sustainable self-employment and self-dependent living requiring simple skills and focusing on women who are excellent agents of change.

5. Community action: increase community awareness through use of better communications: field-based training and counselling to mobilize community support and participation in practical help to help people affected with leprosy in their social acceptance and rehabilitation.
6. Referral and support services: CBR will be successful provided diversified individual needs are met covering physical, medical and rehabilitative areas (but should avoid excessive institutional care) through referral and support services.
7. Discriminatory legislation: all discriminatory legislation must be repeated in countries/states where it exists. Appropriate terminology in relation to people affected with leprosy must be developed with their full consent.
8. Multi-sectorial approach: comprehensive rehabilitation with socio-economic emphasis is possible with involvement of relevant ministries of governments along with support of UN agencies and NGOs. The political commitment at governmental level is imperative.
9. Non-governmental agencies: non-governmental agencies, both at international (e.g. ILEP/ILU) and national levels (leprosy and non-leprosy) are critical in years ahead for their commitment and available resources in promoting rehabilitation. They need to strengthen their activities by acquiring well-trained rehabilitation experts and co-ordinating at field/central levels.
10. Research: ongoing research to find new effective and efficient rehabilitation methods, social aspect research, and market research can make significant improvements for the future.

C. S. WALTER (Moderator)

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Causative organism and host response

Workshop 1—new tools for diagnosis and epidemiology

Our aim for the workshop was to review the state of the art of new tools for diagnosis and epidemiology studies of leprosy and to assess their potential impact on control programmes should they be implemented. We also identified those tools needing further development and testing prior to evaluating as a tool for leprosy control.

SEROLOGY TO IDENTIFY AT-RISK CONTACTS

After several years of extensive investigation it has become apparent that serology with PGL-1 has been found useful in identifying household contacts at high risk of developing multi-bacillary (MB) disease. Since MB disease is potentially the most significant reservoir of *Mycobacterium leprae* with potential for spreading the infection, workshop participants felt that control programmes should begin to explore this application. A 15-min dipstick assay for PGL-I antibody is now available and could be used in field conditions, for example, in small-scale LEC or SAPEL programmes. Important limitations of this test require that it not be applied as a mass screening tool among community contacts but as a specific test applied to 'close' contacts of MB index cases. This application ensures that the test is applied economically to a small group of contacts most likely to develop disease and who potentially represent a major link in the transmission of *M. leprae* among the community. Preliminary evidence suggests that aggressive antileprosy chemotherapy of PGL-I-positive household contacts can reduce the PGL-I antibody titre, while a single dose of ROM has little or no effect. Thus, aggressive prophylactic therapy of PGL-1 positive contacts has the potential to greatly reduce the force of infection in the community. The next step in this area is to define appropriate treatment interventions for this group of at-risk contacts.

MOLECULAR TEST FOR RIFAMPIN RESISTANCE

Tests for drug susceptibility have long been needed in leprosy. We now have one such test capable of detecting mutations associated with rifampin resistance in *M. leprae*. The test is based on DNA sequences found in the rpoB gene and is being tested as a survey tool in Nepal. This survey will establish the current level of rifampin resistance in the area which can be monitored in the future to determine trends in drug-resistance. Molecular studies to define the site for DDS resistance are underway but have not yet revealed the mechanism(s) of resistance. Should it turn out to be associated with mutations in the folate pathway as suspected, then a molecular test could be developed obviating the need for mouse foot pad testing for drug resistance. Other antibiotic gene targets, such as gyr A and B, are being

investigated as sites for resistance to the fluoroquinolones in anticipation of their use in shortening therapy for leprosy.

T-CELL ANTIGENS AND SKIN TEST REAGENTS

New developments in T-cell studies are allowing T-cell responses to *M. leprae* to be measured in large-scale field studies. These include the development of simple, whole blood culture assays to measure T-cell proliferation or cytokine production in response to antigen. These assays are currently being used in Nepal to test the antigenicity of new skin test reagents, and in Malawi to monitor changes in T-cell immunity induced by BCG vaccination in 700 volunteers. Such assays could be used to measure T-cell responses and their relationship to antibody responses in household contacts.

A new tuberculin-like skin test reagent for leprosy could be used to monitor the prevalence of preclinical infection in the community, to monitor interventions and to focus leprosy control efforts. Two initiatives to develop *M. leprae*-specific skin test reagents are underway. Cell wall and cytosolic antigen fractions have been produced in the first initiative. The fractions are depleted of carbohydrates and lipids and go into phase I testing in late 1998. Phase II and III trials are planned for Nepal. Another WHO initiative is screening synthetic peptides for *M. leprae* in a multicentre study to identify *M. leprae*-specific peptide epitopes and preliminary results have identified some promising candidates. Specificity testing must be met prior to advancing these reagents in the study protocol. It is anticipated that completion of the genome project may give rise to other *M. leprae*-specific proteins useful for testing as potential skin test reagents.

NASAL CARRIAGE OF *M. LEPRAE*

An important area gaining much interest involves defining rates of nasal carriage of *M. leprae* in leprosy endemic communities. PCR for *M. leprae* DNA and monoclonal antibody-directed staining of *M. leprae*-specific antigen have been used successfully for this purpose. Initial results range between 3 and 9% positivity in household contacts of MB and PB index cases. New large-scale studies need to be performed to determine the relationship between transient contamination of the nose, continuous carriage of the bacilli (colonization?) and development of lesions on the nasal mucosa. Results from these types of studies may be pivotal in determining maintenance of an *M. leprae* reservoir in the community and eventually how *M. leprae* is transmitted. Studies to improve the reliability of these types of assays need to be performed. For example, large-scale screening of uninfected individuals needs to be performed to establish realistic levels of false-positive rates using these very sensitive assays.

Participants: T. Gillis, Chairman, P. Brennan (Rapporteur), Sang-Nae Cho, Maria DaGraca S. Cunha, Jim Douglas, Stella Van Beers, Francoise Portaels, Hazel Dockrell, Tranquilino Fajardo, Utpal Sengupta

Workshop 2—chemotherapy

The participants in the workshop agreed to the following:

Because the global prevalence of leprosy has decreased dramatically, treatment delivery

systems have to be adapted to the new reality, and it will be difficult to maintain everywhere the supervision of monthly doses of rifampicin. However because the present anti-leprosy drug regimens (WHO-recommended MDT) are so extremely effective and robust, these regimens should remain the treatment of choice for leprosy in national programmes. The robustness of the regimens and the systematic use of blister-packs enable less reliance on the direct supervision of monthly drug intake by the general health services.

Considering the effectiveness of the 2-year WHO-MDT for MDT leprosy, the changes in definition of PB and MB and the low BIs in the majority of MDT patients, shortening the duration of treatment of MB leprosy to 12 months is justified. Similarly, the use of single dose rifampicin-ofloxacin-minocycline (ROM) for the treatment of single lesion leprosy offers great operational advantage to national programmes. It should be understood that the current WHO recommendations represent minimal guidelines.

Except for the treatment of single lesion leprosy with ROM, use of the new drugs at the present time should be strictly limited to special circumstances, for example proven rifampicin resistance. The development of new drugs and regimens is encouraged and should continue to be a priority in the area of chemotherapy.

Drug resistance is not a problem at the current time and is not expected to increase in the future, even with shortening the duration of treatment of NO cases to 12 months, as long as the drugs are used in appropriate combinations. To replace mouse footpad inoculation, research should continue on molecular methods of detecting drug resistance.

Finally, it is crucially important for the survival of leprosy control programmes that the supply of drugs after the year 2000 be assured.

Participants: Jacques Grosset, Chairman, Scott Franzblau (Rapporteur), Robert Hastings, Paul Roche, D. V. A. Opromolla, Baohong Ji, Lou Levy, Diana Williams

Workshop 3—epidemiology/transmission/vaccines

The workshop attendees addressed the four major topic areas outlined and came to the following consensus opinion.

LEPROSY TODAY—PATTERNS AND TRENDS

Routine 'prevalence' data generated in recent years, in most countries of the world, have been greatly influenced by 'operational' factors (e.g. changes in ascertainment, diagnostic and classification criteria, treatment duration etc.). As such they may not, and often do not, reflect the underlying epidemiological situation, and can only be interpreted in the context of clear explicit information on these underlying factors over the time period covered by the data.

We recommend that all tables, figures and reports which purport to represent leprosy 'prevalence', 'incidence' or 'case detection' patterns or trends be accompanied with clear and explicit captions specifying the operational factors (ascertainment methods, case and classification definitions, treatment durations, etc.) employed during the entire period to which the data refer.

Leprosy frequency and patterns often differ greatly between various segments of populations. This heterogeneity at national, district and local level is not evident in crude summary statistics, which can thus lead to a distorted picture of the actual situation.

Whenever possible, an effort should be made to separate high prevalence populations from other group data, or at least to point out how crude data are effected by their inclusion (e.g. data from Asia, Africa and Latin America are heavily influenced by India, Ethiopia, Madagascar and Brazil, and national data for each of these areas are influenced by other area-specific operational/historical factors.

NEW INSIGHTS INTO THE NATURAL HISTORY OF LEPROSY

Evidence for zoonotic leprosy in armadillos of the southern United States is now overwhelming. It is no longer correct to claim there is 'no extra-human reservoir' of *M. leprae*. The relevance of primates in leprosy's natural history remains anecdotal but deserves more rigorous study including surveys in the wild and studies of human risk associated with primate contact. Any realistic consideration of leprosy eradication must contend with this issue.

Recent PCR-based data on widespread presence of *M. leprae* in nasal cavities of individuals in endemic populations, and in environmental samples are potentially very important for our understanding of the natural history of leprosy. Some of these studies have, or appear to have, been influenced by appreciable numbers of false positives. To ensure credibility, such studies require rigorous controls to demonstrate high specificity of the assay used (preferably inclusion of large numbers of blind coded samples, from non-endemic populations, among the study samples). Presentation of such data by age, sex, contact status and area will enhance interpretability and credibility. Appropriate multivariate analysis should be carried out in order to ensure proper control of confounding factors.

The predominate portals of entry or exit of *M. leprae* are still unclear. Recent studies emphasizing nasal carriage and mucosal immunity reflect interesting hypotheses but are not yet convincing in themselves. If the presence of *M. leprae* in nasal cavities reflects transient carriage (the nose acting as an air filter), the data could also be consistent with skin as a portal of entry. Large, carefully conducted, long term studies will be required to solve this issue.

DOES CHEMOTHERAPY REDUCE TRANSMISSION?

Though it is logical to infer that effective chemotherapy must reduce the risk of infection with *M. leprae*, and consequent incidence of leprosy disease, at least to some extent, it is extremely difficult to demonstrate such an effect convincingly. Leprosy incidence is obviously strongly influenced by environmental or behavioural correlates of socio-economic development. Given that individuals may be infectious for long periods prior to diagnosis and treatment, the effect of even a good treatment programme on the overall leprosy incidence may be small. The issue of MDT's impact on leprosy incidence, though of obvious political importance, may well be beyond the reach of convincing epidemiological evidence.

VACCINES IN LEPROSY

The variability of BCG's efficacy between populations remains unexplained. The fact that BCG's effect in tuberculosis shows analogous variability enhances the importance of this issue for public health impact, and hence for research. The efficacy of BCG appears to decline with time. There are no data on whether BCG has any influence greater than 20 years after administration, either against leprosy or against tuberculosis. Since BCG has been given at

birth in most countries for the past 20–30 years, it is now possible to study the influence of BCG in infancy on adult disease incidence. The evidence from Venezuela, Malawi and Burma that repeated BCG enhances its protective effect against leprosy increases the potential importance of such studies. The ongoing trial of a second dose of BCG among school children in Brazil will provide important data on this very practical intervention.

Research into the immunology of leprosy and into leprosy vaccines should be linked to the major international research effort devoted to tuberculosis. Comparisons between the two infections/diseases will provide useful insights. Leprosy should be included as an outcome in any future trial of a tuberculosis vaccine. The current interest in post-exposure vaccines against tuberculosis could also have implications for potential leprosy interventions either in high risk populations or in therapeutic context.

Participants: Paul Fine (Chairman), R. Truman (Rapporteur), G. Bjune, K. V. Desikan, A. Diallo, V. K. Edward, M. D. Gupte, J. D. Habbema, S. Izumi, C. K. Job, C. M. Martelli, A. Meima, R. G. Reddy

Workshop 4—nerve damage and reactions

1. Nerve damage continues to be a major problem.
2. Nerve damage remains poorly understood.
3. Controlled trials of current and future therapies are urgently needed.

The participants discussed the epidemiology and pathogenesis of neuritis and reactions, and the currently recommended therapies.

Epidemiologically, MB disease and age (15–44 years) appear to be major risk factors for the development of reactions and nerve damage. The group noted the absence of good data relating to the relationship between reactions and endocrine alterations such as pregnancy and adolescence. Data were also presented showing that we may expect 40% of patients to now have their first reactional episodes after completing MDT. This has very important implications for management. Patients will need to be carefully warned about reactions advised to seek care promptly when symptoms develop. It was also noted with concern that neuritis may develop in some patients long after apparent cure.

The group noted success in the use of sensitive tests to evaluate sensory function in many centres. However, it is important that the reliability, diagnostic cut-off, specificity and sensitivity of these tests is carefully considered. Scoring systems derived from these tests should be developed in a logical manner, such as ensuring that scores are recorded for individual nerves. Functional outcome is also an important measure that needs to be considered as well as motor and sensory function. It was also noted that occupation and resultant mechanical nerve stress may have affected outcome.

Nerve injury may occur in three phases:

1. Localization of *M. leprae* to nerve, followed by
2. Active neuritis, and
3. Late nerve damage

Evidence was presented that armadillo nerves may be a useful model for lepromatous nerve involvement. Tuberculoid type nerve damage seems to occur in murine nerves directly injected with *M. leprae*.

Studies from Mumbai indicate that viable *M. leprae* can be recovered from the nerves of patients who have completed MDT. The clinical significance of this finding is not yet known.

The immunological basis of reactions and neuritis was briefly reviewed, and several lines evidence indicate that TNFα may play a key role in these processes. Other cytokines may also have critical roles in reactions. Several previous Congress workshops have discussed the difficulty in distinguishing between a late reaction and relapse in nerve. This remains a clinical and pathologic challenge.

In its consideration of current treatment of reactions, the group expressed concern that there is an absence of data from controlled clinical trials relating to doses of corticosteroids and duration of treatment. There was also concern that the doses and duration of treatment recommended by the WHO 7th Expert Committee (Geneva, June 1997) are too low and too short.

Multicentre trials are currently in progress in India to determine the optional length of treatment with corticosteroids. A randomized control trial of prophylactic corticosteroids to prevent reactions and nerve damage in new MB patients is being done in Bangladesh and Nepal.

The workshop discussed the need to evaluate currently available immunosuppressants as second-line treatment for patients who do not respond to corticosteroids. Multicentre trials are also needed to define the role of neurolysis in the management of acute neuritis. All of the above mentioned multicentre trials are required in order to generate high quality evidence for the best treatment of leprosy patients. Funding such trials should be a high priority.

CONCLUSION

The workshop participants expressed confidence that this combination of careful and appropriate patient evaluation, studies on pathogenesis, and high quality clinical trials will lead to improved care for leprosy patients.

Participants: D. Lockwood (Chair); D. Scollard (Rapporteur), W. Britton, R. Jerskey, R. Barnetson, B. Naafs, Dr Antia, A. Anderson, S. Suneeta, P. Saunderson, Dr Shetty, E. Sarno, E. Sampaio

Workshop 5—pathogenesis and lessons from leprosy

Scientifically, the opportunities for studying pathogenesis in leprosy could not be more timely. The availability of the complete sequence of the M tuberculosis genome and the considerable inroads that have been made in to sequencing the *M. leprae* genome, mean that we will be able to identify genes associated with particular biological properties by sequence comparison. Techniques for genetic exchange between mycobacteria will make it possible to test for gene functions in a way which is not possible with the non-cultivable *M. leprae*. Additionally, novel approaches for developing new animal models (gene knockout and transgenic animals) developing at a rapid pace; these will prove invaluable for testing hypotheses relating to control of infection and immunopathological mechanisms.

We believe that it is important to continue to address questions of pathogenesis for two broad reasons. Leprosy is a paradigm for intracellular infections. Comparative pathogenesis studies will provide important information for understanding not only leprosy, but infectious

processes in general. There are many important lessons that can be learned from the study of leprosy. Secondly, the consequences of the host–pathogen interaction remain a clinical problem for the leprosy patient for many years after bacteriological cure has been achieved. Rapid advances have been made in the pharmaceutical and technological fields for developing novel approaches to such things as wound healing, the treatment of immunopathological conditions, and other infections. However, these industries are not interested in leprosy and it will be up to us to exploit the developments for the treatment of leprosy patients. An understanding of the mechanisms involved in leprosy will enable us to make informed decisions as to which are likely to be useful for the leprosy patient.

We would regard the following as priority areas:

1. Completion of the genome sequencing project and comparative genomics with related organisms. This will enable us to understand what is biologically unique about *M. leprae* and hence to provide clues for the molecular basis of its pathogenicity.
2. Proteomic analysis, which will complement the genomic approach, will help us to understand which proteins are important for survival within the infected host. Once these proteins have been identified, further genetic studies can be undertaken.
3. New animal models, including transgenic and knockout mice, will play an important role in exploring pathogenesis. For example, mice with specific immunological deficiencies will enable us to determine important pathways in host immunity. These studies require highly specialized facilities and expertise, such as those available in mouse foot pad laboratories, which are in danger of being lost; in order to exploit these new models, it is important that these be maintained.
4. Molecular approaches to characterizing the interaction between *M. leprae* and the Schwann cell will enable us to further understand the unique pathogenic mechanism of *M. leprae*, and will complement clinical studies on nerve damage.
5. Host response to *M. leprae* is still poorly understood. The role of such factors as host genetics in determining susceptibility to infection and/or immunopathology will provide important pointers to the mechanisms involved.
6. New approaches to investigating the molecular details of immunological recognition could have important practical applications for detecting infection.
7. We believe that it is important that an integrated approach to the study of pathogenesis should be encouraged. A great deal can be learned by drawing on the expertise available in related fields such as neurobiology, immunology and molecular biology.

Participants: Jo Colston (Chairman), Linda Adams (Rapporteur), Christina Pessolani, Tom Ottenhof, Stewart Cole, Yasuo Fukutomi, Rabia Hussain, Delphi Chatterjee, James Krahenbuhl.

Summary

Whether or not the leprosy elimination target is met in all endemic countries by the year 2000, the MDT programme will have greatly reduced worldwide prevalence. However, our workshop chairmen were asked to ignore the prevalence-based leprosy 'elimination' programme and focus on recommendations for a long term, incidence-based eradication target where transmission is blocked. They were asked to be concerned with basic leprosy research goals in the post 2000 era.

The members of our workshops are actively productive workers, committed to their special interests. They are fully cognizant of the obstacles faced daily in working with leprosy and *M. leprae*, the requirement for clever experimental design even with the availability of the powerful tools of molecular biology which can now be brought to bear on some of the research obstacles. They are also aware of our lack of understanding about leprosy and *M. leprae*. How do you block transmission if you don't know how infection is transmitted? Can infection be detected, diagnosis made earlier? Is there a non-human reservoir host, a carrier state, an environmental source? What is the basis of *M. leprae*'s predilection for nerves, the mechanisms underlying reactions? What needs to be targeted to treat reactions? Can a vaccine play a role?

There is nothing startling in the workshops' recommendations. Other individuals and groups of experts have made the same suggestions, with slightly varying priorities. What one can read between the lines of these reports, is a sense of urgency to get as much done as soon as possible. Worldwide interest in leprosy will soon be diminished, not by design but as a consequence of the laudable success of the MDT programme. The experiment is still underway, but chemotherapy alone, killing bacilli in the detectable human host, does not appear to be the answer to blocking transmission.

A number of goals must be addressed while there are still intact national and international leprosy programmes, while there are still leprosy treatment and research centres that can co-ordinate and facilitate the necessary trials for early diagnosis, early detection of reactions, evaluation of immunosuppressive regimens for reactions. A key recommendation is concerned with the means of measuring progress. A clear and explicit means of reporting incidence, prevalence and 'case detection' should be implemented to avoid a distorted picture of worldwide leprosy.

These recommendations are non-controversial. What should be done is clear. The uncertainty is in determining who will do the work. Who will fund the laboratories engaged in this work? Look around you. There are fewer scientists attending this Congress but browsing the abstracts and attending our sessions and posters clearly revealed to me that fewer of us are doing far better work than in the past. Alternative sources of funding will help. Tuberculosis research is enticing researchers away from leprosy in the developed countries but is visibly sustaining leprosy research in many centres in developing countries. Formation of alliances was a key goal of this Congress. I asked my colleagues from Carville to identify in their own discipline, dedicated people, committed laboratories that will sustain their leprosy research efforts over the next 5, 10 or more years. These are the people with whom we wish to collaborate, form alliances, share resources and expertise, address the future of worldwide leprosy.

JAMES L. KRAHENBUHL
(Moderator)

Lepr Rev (1999) **70,** 103–109

Teaching Materials and Services

Evaluating rural resource centres: guidelines from UNESCO

Community resource centres are emerging as one of the most favoured of the information delivery strategies in rural areas. Such centres not only provide sources of information but advice and guidance as well. Information formats are accessible by those who cannot read as well as the literate and newly literate. They act as centres for all agencies involved in information provision. They link external knowledge with indigenous knowledge. They repackage information and act as centres for information sharing. The community itself plays a crucial and active part in their establishment and maintenance.

There is now a need to assess how effective such centres are in providing the information that will lead to social and economic development of rural communities. UNESCO, on behalf of IFLA, has recently published guidelines for measuring performance and impact. The expectations of any rural information support system are isolated, described and discussed. Indicators have then been developed against which the expectations can be measured and suggestions are provided as to how these indicators can be applied to provide more efficient and effective information provision. Both expectations and indicators are based on the experience and practice of rural information provision, as revealed by the literature.

The indicators show: how effective centres have been in securing relevant resources; whether there have been increased opportunities for all sections of the community to access and use relevant information sources; how effective centres have been in management, planning and exhibiting accountability and whether the activities of the centres have had a positive impact on improving socio-economic conditions, extending the knowledge base of the community and increasing participation in government and extension programmes.

The publication is available free of charge from UNESCO:

Division of Information and Informatics
1 rue Miollis
75732 Paris Cedex 15
France

Rural Information Provision in Developing Countries:
Measuring Performance and Impact.
Paris: UNESCO, 1997.
(CII-97/WS/11)

Certificate in Pharmacoepidemiology and Pharmacovigilance at London School of Hygiene & Tropical Medicine

The challenge of maximizing drug safety yet maintaining public confidence has become increasingly complex. Pharmaceutical companies are required to employ named members of staff responsible for

pharmacovigilance. Health authorities grappled with the need to provide quality care whilst containing a burgeoning drug budget. Regulatory authorities must balance the potential benefits of new drugs with varying levels of suspicion of their potential harm.

This 20-week examined course in pharmacoepidemiology and pharmacovigilance addresses the increasing need for well informed professionals to work in all areas related to the assessment of drug safety and risk-benefit of drug use. It is an introductory course and should meet the needs of a wide variety of practitioners.

The course is part-time and comprises 175 hours (approximately one day per week) which are spent as follows: 55 hours formal teaching and contact time, 70 hours self-directed study and 50 hours project work. Formal teaching will take place during three sessions in 1999; 16–19 February, 13–15 April and 1–3 June. Participants will also be supported outside this time by a personal academic advisor.

The course is aimed at personnel concerned with the safe use of medicines in developed countries, including those working (or intending to work) in:

- the pharmaceutical industry who are involved in drug development, licensing, and surveillance
- regulatory bodies who are involved in licensing and surveillance

Further information: The Registry, London School of Hygiene & Tropical Medicine, 50 Bedford Square, London WC1B 3DP. E-mail: registry@lstm.ac.uk

Essential Surgery in Leprosy. Techniques for District Hospitals. H. Srinivasan and DD Palande. WHO, Geneva

The back cover summary of this WHO publication (WHO/LEP/96.2) reads:

This handbook provides practical training and service guidance to doctors in general hospitals about essential surgical procedures and techniques for individuals who have impairments and deformities due to leprosy. The procedures can correct deformities as well as prevent disabilities or arrest the worsening of disabilities.

The book is divided into two sections. Part I describes procedures which can be carried out at district hospital level. It covers procedures for the care and treatment of infections and ulceration of hands and feet, and for decompression and management of nerve abscesses to save nerves from paralysis, as well as simple techniques for eyelid paralysis. Part II includes more complicated procedures, such as tendon transfer. These require greater expertise and training, and must be supported by competent physiotherapists.

It is expected that the person using this handbook is already a qualified surgeon, or has had training and extensive experience in surgery. Although such expertise and experience will already exist in many general hospitals, the procedures and techniques may not be known to doctors because they have been performed only in a few specialized leprosy institutions. It is hoped that this handbook, by providing detailed descriptions of the procedures with a generous use of clear illustrations, will make it possible for leprosy-affected individuals to benefit from services offered in general hospitals, including those at the district level.

Main chapter headings include: general considerations, the promotion of healing of plantar ulcers, prevention of recurrent plantar ulceration, infections of the hand, decompression of nerve, nerve abscess, correction of lagophthalmos, correction of foot drop, correction of paralytic deformities of the hand, correction of paralytic claw-fingers, correction of paralytic claw-thumb deformities.

Published 1996. A4 format, 135 pages. Price not stated. *Further information*: Action Programme for the Elimination of Leprosy, WHO. CH-1211, Geneva 27, Switzerland.

A Guide to Funding from Government Departments and Agencies

The Directory of Social Change (Publications), 24 Stephenson Way, London NW1 2DP, United Kingdom, Tel 0171-209-5151. Fax 0171-209-5049. E-mail info@d-s.demon.co.uk, has released the above Guide (£18.95), with the following description:

The only comprehensive guide to £2 billion a year of government funding. It covers 16 government departments, including the Welsh, Scottish and Northern Ireland Offices, and over 50 related agencies, revealing a possible **200 sources of funding** for voluntary sector organizations.

It includes
- special grant programmes open only to the voluntary sector
- agency programmes open to both the public and private sectors
- special departmental initiatives to pilot new approaches
- annual grant-in-aid to specific voluntary organizations

For each programme the guide shows the following:
- Departmental context
- Annual funding available compared to previous years
- Analysis of grant-making
- Policy guidelines & exclusions
- Application deadlines and advice sources
- Contact name and address

The guide also explains:
- The responsibilities of each department
- The impact of regional government
- The conventions covering government funding applications
- The civil service hierarchy

'*Clinical Tuberculosis*' by John Crofton, Norman Horne and Fred Miller; yearly report from TALC, UK

Teaching Aids at Low Cost (TALC), PO Box 49, St Albans, Herts AL1 5TX, United Kingdom, Tel +44(0) 1727 853869. Fax +44(0) 1727 846852, has issued a progress report, August 1998.

Present background. WHO has declared the world epidemic of tuberculosis a global emergency. The situation is now exacerbated by the explosion of HIV and the rising threat of multidrug resistance. The usefulness of the book has been emphasized by the enormous demand for it in many countries and its translation into many languages. We expect an equal demand for the second edition now in production. Publication is expected in late 1998.

Purpose of the book. The book was written in simple English (with a glossary) for non-specialized doctors, nurses and health assistants in the Third World. Commissioned by TALC, it was published in the UK by Macmillans in 1992. It was sponsored by the International Union Against Tuberculosis and Lung Disease (IUATLD) and financially supported both by WHO and by a number of national and international charities.

Publication and costs. With financial support from donors it was sold at a low price (£3) in poorer countries and provided free in the poorest. (A subsidy from the British Government enabled one reprint of 1000 copies to be sold at £2). In industrialized countries the full price has been £10·99. The authors receive no fees or royalties.

Distribution, translations and use. We calculate that nearly 76,500 copies in 16 languages have been distributed in 124 countries (with 4000 copies in Urdu and Bengali in progress). We arranged the French, Spanish and Portuguese translations for use where each was the appropriate second language.

Requests to produce the other translations mostly came from professionals in the relevant countries. Some needed subsidies for translation and/or publication costs. Editions in two more languages, Urdu and Bengali, are in preparation. A request has also been received for permission for an Uzbek edition.

The book has been extensively used in national and international training courses. We encourage local reproduction of extracts as long as these are not used for commercial purposes. The book is recommended for further reading in a number of WHO publications.

Second edition. The major changes in the forthcoming second edition are revising the treatment sections to conform with the latest WHO/IUATLD recommendations and a considerable enlargement of the chapter on HIV and tuberculosis. In addition, the whole text has been reviewed and, when necessary, revised.

Financial needs. Judging by the remarkable demands for the first edition we will require extensive help to provide free or cheap copies of the second English edition in poor countries. We will also need funds for the costs of translation and publication in a number of languages in which the first edition has appeared.

The Wellcome Trust Training & Fellowships for Research into Infectious Diseases for Scientists from Tropical & Developing Countries

The trust recognizes the continuing threat of infectious diseases in tropical and developing countries and wishes to develop research expertise which is sustainable in these countries in order to address health problems arising from infectious diseases. The awards are intended to provide both training and research experience for applicants, who must be based in a developing or tropical country. The training will be obtained at international centres of excellence in either the UK, Republic of Ireland, or any country in the developing or restructuring world, and a substantial period of research will be undertaken in the applicant's home country. For instance, a four-year award would normally include a minimum of two years' research in the home country over the period of the award. AIDS/HIV-related studies relevant to tropical regions are fully supportable.

Eligibility

Applications are invited from postdoctoral basic scientists or medical graduates of up to six years' research experience (postdoctoral) who are nationals of developing countries. Applications may be considered in exceptional circumstances from those who are educated to first degree or Master's level, who are able to demonstrate substantive potential for research and operational leadership and who have research experience equivalent to a PhD, as evidenced by their publication record. Applicants will wish to become independent research scientists through high-quality research into infectious diseases of regional significance to their home country. The research proposal must include a clear argument outlining the relevance of the project to the home country. Applications will be assessed on the basis of the candidate's achievements in research, the scientific merit of the proposal and the appropriateness of the research for the proposed location. The nature of the training component and the training site chosen must be appropriate for the proposed research.

Funding

Awards will be for a maximum of four years, non-renewable. Fellowship support may include a salary/stipend appropriate to the countries in which the candidate will be studying/working, as well as project-dedicated and travel expenses. All expenses must be fully justified. Consideration may also be given to the expense of attending a course leading to a recognized qualification in a discipline relevant to the fellowship research programme.

Application procedure

The preliminary approach to the Trust should include an outline of the proposed research, an approximate budget and curriculum vitae of the applicant, together with a written guarantee of subsequent employment from the host institution in the applicant's home country and a letter of support from a suitable sponsor at the training institution. Applications will be considered throughout the year.

Further information about the initiative can be obtained from:

The Grants Section (Tropical)
The Wellcome Trust
London NW1 2BE
Tel: 0171 611 8409
Fax: 0171 611 7288

Information is also available on the Web: www.wellcome.ac.uk

NB: Applicants may not apply for more than one Trust fellowship scheme at any one time.

University of London External Programme

The London School of Hygiene & Tropical Medicine is a research-led postgraduate medical school of international standing with nearly 100 years of research and teaching experience in the field of public health and tropical medicine. The School encompasses the largest group of epidemiologists and statisticians in Europe.

This new distance learning course will be offered through the University of London's External Programme from September 1999, and will soon join the MSc & Postgraduate Diploma in Health Systems Management, and MSc & Postgraduate Diploma in Infectious Diseases which are being introduced in September 1998.

The level of teaching and assessment throughout the course will be of the same excellent standard as that of Internal students.

Who should apply?

This new Masters degree and diploma are appropriate for people from a range of professions, disciplines, cultures and countries, who are interested in, or are already working in the field of epidemiology and public health.

Admission criteria

MSc: A second class honours degree or the equivalent, in health related disciplines or in statistics or another appropriate subject. Work experience in a health science/health care setting is desirable but not essential. Candidates with an appropriate professional or technical qualification in a health-related field, together with at least three years' relevant experience, which satisfies the University as a qualification equivalent to a second class degree will be considered on an individual basis.

Postgraduate diploma: A degree or an appropriate professional or technical qualification which satisfies the University as a qualification on the same level as a degree. Work experience in a health sciences/health care setting is desirable but not essential.

Study materials and study support

This programme will be primarily computer-based; students will be provided with unit study packages in CD format/disk or print. These packages will consist of a variety of comprehensive, lively and interactive materials, including, where applicable:

- original materials, containing the core element of the unit; self-assessment exercises; sample examination questions
- a student guide with information on planning studies, preparing for examinations and study techniques
- a student manual on installation and operation of software- and computer-based materials
- a reader/resource pack; textbooks

The nature of course delivery necessitates that students have access to a computer with minimum hardware requirements, and to email. Students will be provided with all the materials they need to do the course, so will not require access to a library.

Students will be allocated a personal tutor and course tutor for each unit who will provide feedback on questions arising from their work.

How long will it take?

Students may complete the Postgraduate Diploma in one year and the whole MSc in two. However, students may take up to five years to complete their studies.

Occasional students

The Occasional student programme will appeal to those who wish to study a particular unit for general interest or specific training reasons.

Application and registration

Application deadline:	30 June 1999
Registration deadline:	31 July 1999
Course starting date:	14 September 1999

Fees

Diploma:	
Registration:	£500 + four core units @ £750 = £3,500
Masters:	
Registration:	£500 + four core units @ £750 + six advanced units @ £273 + Project report @ £812 = £5,950
Occasional student:	composite fee of £1,000 for a core unit or £522 for an advanced unit

The Fifth Asian Dermatological Congress, Beijing, China: 14–17 October 1998

Under the concerted effort of the Congress Organizing Committee, the 5th Asian Dermatological Congress was successfully held at the Beijing International Convention Center on October 14–17, 1998.

The theme of the congress was 'Oriental Medicine Toward the World'. More than 700 dermatologists from various parts of China and more than 400 colleagues from abroad attended the Congress. Apart from the delegates from Asia, the Congress was well supported by dermatological experts from the United States, the United Kingdom, Canada and many European countries.

Twenty-five plenary lectures were given by the invited distinguished attendants at the Congress, covering a wide range of dermatological topics, including 'Immunobiology of the skin' by Dr Stephen I. Katz from the National Institute of Arthritis and Musculoskeletal and Skin Diseases of the USA, 'Dermatology in the 21st century' by Dr Klaus Wolff from the University of Vienna in Austria and 'Study on risk of leprosy relapses in China' by Dr Xiangsheng Chen from the National Center for STD and Leprosy Control of China. A total of 14 scientific sessions were spread over the 3 days, with both oral and poster presentations. Areas covered included basic science in dermatology, psoriasis, autoimmune skin disorders and infectious skin disorders.

Leprosy was included in the session of infectious skin disorders and there were five scientific papers on leprosy presented at the Congress, despite the fact that the 15th International Leprosy Congress had taken place at the same venue just 1 month before.

The Congress was organized by the Chinese Society of Dermatology and co-organized by the Beijing Medical University, the Peking Union Medical College and the Capital University of Medical Sciences under the auspices of the Asian Dermatological Association and the Chinese Medical Association.

The sixth Asian Dermatological Congress will be held in Thailand in 2001.

Xiang-Sheng Chen,
National Center for STD and Leprosy Control,
Institute of Dermatology, CAMS & PUMC,
Nanjing, China

Lepr Rev (1999) **70,** 110–123

News and Notes

Romania: 'Ceausescu's old clothes go to the last leper colony'

The *Guardian* newspaper (UK) of Thursday November 1998 reported that in a final act of post-communist restitution, Europe's last leper colony is to receive the finest clothes once worn by Romania's former dictator, Nicolae Ceausescu, and his wife, Elena.

They will be sent to Tichilesti Hospital in Isaccea, a centre for leprosy patients which, for more than 40 years of communism, was officially considered non-existent. Isaccea is still not sign-posted. Access is by a winding dirt track off the main road. Contact with the outside world remains an alien concept for most of its 34 leprosy patients, aged between 30 and 90. The article reports that the allocation of clothes will include crocodile skin bags, mink furs and gold-thread bathrobes, part of a collection of thousands of objects from the Ceausescu estate, filling 1000 square metres and now up for disposal.

Change at last at WHO

The following appeared in the *British Medical Journal*, 1998, 317, 1 August, page 295:

Dr Gro Harlem Brundtland has done what most people hoped she would. On her inauguration as director general of the World Health Organisation, she has swept away the existing secretariat (though keeping some members on as advisers), and announced her own carefully chosen cabinet to an increasingly optimistic staff. Of the 10 new appointments, eight come from outside the organisation and six are women. There is an even split between the north and south, and all of the WHO's six regions are represented. Along with the new cast come plans for a new way of working—reducing overlap and increasing convergence between individual programmes.

The speed of the appointments has taken the organisation by surprise, and one appointment in particular is causing concern. Michael Sholtz, who is to be responsible for health technology, will be in charge of the action programme on essential drugs, the WHO's key initiative to provide poorer countries with appropriate and affordable drugs. Dr Sholtz comes from the pharmaceutical industry and has little experience of the developing world. Dr Brundtland has portrayed the appointment as providing a liaison between the industry and the WHO. Dr Sholtz will have to prove his allegiance at a tough time for world health, when the development of effective but expensive drugs for AIDS has brought to a head the north-south fight over drug patent rights.

So far the changes all relate to the WHO's headquarters in Geneva, where Dr Brundtland has executive powers to hire and fire. The more difficult and perhaps more crucial test of her ability will be in dealing with the WHO's six regions, over which she has no direct control. Regional directors are elected by their constituent countries rather than appointed by the director general, and they can hire and fire staff within their regions. Especially important is their responsibility for appointing country representatives—the WHO's front liners, who, because of lack of training and resources, form one of the weakest links in the WHO's chain of influence.

The regions have always presented the WHO's leaders with a problem. But Dr Brundtland must take them on after 10 years of unchecked autonomy and at a time of strong support from their constituent

countries. Regional meetings have become an important forum, especially for developing countries—many of whom feel that their voice at the World Health Assembly has been eroded by northern dominance and by decline in the assembly's influence.

Dr Brundtland clearly understands the need to woo the regional directors, three of whom were her rivals for the director general's post. A retreat is planned for the end of the month, which all six regional directors will attend. This seems designed to set the tone for the annual round of regional meetings in September and October and to establish a process for streamlining the currently diverse regional structures and methods of working. The fate of the country representatives is also likely to be on the agenda: Dr Brundtland is understood to want to meet them in person and to strengthen their ties with headquarters. Meanwhile, money is to be made available to install proper communications between the regional offices and headquarters. This will allow frequent video conferences so that regional directors will become actively involved in policy making. In Dr Brundtland's phrase, there will be one WHO speaking with one voice. If she can achieve this politically difficult internal alliance, the WHO may again at last become an effective advocate for world health.

WHO Press Release, November 1998, 'Asia is 'epicentre' of World's tuberculosis emergency'

Press Release WHO/87 of 23 November 1998 reads as follows:

HIV, multidrug-resistant TB and financial crisis increase TB threat to the region

Bangkok – Asia is the epicentre of the world's TB emergency and must become a top priority among international efforts to control the disease, according to Dr Gro Harlem Brundtland, Director-General of the World Health Organization.

In a statement today (23 November) at the Global Congress on Lung Health, 29th World Conference of The International Union against Tuberculosis and Lung Disease (IUATLD), Dr Brundtland warned that unless there is concerted action in Asia, the epidemic will continue to rise, jeopardizing global control efforts.

'Our ability to control the spread of TB pivots on Asia – now the epicentre of the world's TB epidemic,' said Dr Brundtland. 'If we cannot control TB in Asia we will never stop TB globally. Factors such as HIV, multidrug-resistant TB and the financial crisis converging in this region are increasing the complexity of the epidemic, making it far more difficult to contain.'

Six high-burden countries which account for over 50 percent of the TB epidemic are in Asia. According to WHO estimates, 4·5 million of the eight million new cases that occur each year are in India, China, Bangladesh, Pakistan, Indonesia and the Philippines.

'We are at a crossroads in TB control,' said Dr Brundtland. 'We can allow the global TB epidemic to become more deadly and strengthen its grip on the world. Or we can act now to reduce the suffering and deaths. We can and must strike back with the tools that we have.'

Dr Brundtland issued her statement at a meeting attended by 1500 delegates from around 90 countries. The Global Congress on Lung Health was organized by the Anti-Tuberculosis Association of Thailand (ATAT) in collaboration with the Ministry of Public Health and the Thoracic Society of Thailand, and sponsored by IUATLD. This is the largest meeting of lung disease experts to be held in Asia in a decade.

'We cannot afford to lose the battle against this age-old killer,' said Professor Don Enarson, Director of Scientific Activities of IUATLD. 'We can cure TB. But we not only need political commitment at national level, but also internationally. We face a major political challenge.'

WHO is concerned that the problem will be compounded by three factors: multidrug resistant TB (MDR-TB), HIV and the economic crisis. Surveys in selected sites in Asia show high levels of MDR-TB that cannot be treated with the most powerful anti-TB drugs. Experts predict an increase in the number

of TB cases as a result of HIV. HIV weakens immune systems, increasing TB transmission to both HIV-positive and HIV-negative people. By the end of the century, HIV will cause three quarters of a million new TB cases globally that would otherwise not have occurred.

WHO is also concerned that a decline in the standard of living in the region could increase the spread of communicable diseases such as TB, and in a climate of changing health sector priorities, some disease programmes lose critical funding.

The 1998 WHO report on the TB epidemic, *TB: A Crossroads*, released at the meeting, documents the consequences of inaction in countries that are not investing in effective TB control. One of the biggest problems is that high-burden countries are not implementing effective control. This includes failure to invest in good quality TB drugs.

The report also describes the progress made by thousands of people around the world who are using the DOTS strategy to stop TB. DOTS is recommended by WHO and IUATLD as the most effective and affordable way to detect and cure infectious TB patients. The strategy not only involves direct observation of treatment. It also requires political commitment, microscopy services, reliable drug supply and monitoring of patient progress toward cure.

Over one hundred countries are now using DOTS. In the last three years, one million TB patients have been treated with DOTS. In some areas where DOTS has been introduced, death rates have been reduced fivefold to less than five percent. Cure rates in half of China where DOTS is being used are 95 percent.

'Three years ago, TB was made a priority here in Thailand,' said Dr Songkram Supcharoen, Chairman of the Organizing Committee of the Global Congress and President of IUATLD. 'In the last year, coverage increased fourfold. The government has committed to a five-year plan to ensure that every patient in Thailand has access to DOTS.'

Dr Brundtland invited participation in a new 'Stop TB' initiative to catalyse a global coalition of partners from all sectors of society, led by WHO, to address the problem of TB in Asia and the rest of the world, and to encourage the use of DOTS more widely.

The Stop TB initiative will develop a global action plan for TB control which identifies the role of different partners. The initiative will focus on a global charter to secure commitments to improve TB control from Heads of State of endemic countries, international organizations including from the UN family, and donors. It will develop mechanisms to ensure global access to quality, fixed dose combination TB drugs.

Urgent action focussed on high burden countries, the emerging MDR-TB problem and management of TB control in settings of high HIV prevalence is also planned. The initiative will support a balanced agenda for global TB research focusing on short- and long-term results.

'By elevating TB control to a political level, there is so much more that we can do,' said Dr Brundtland. 'I urge you to take the right course, support the new initiative and join us to use DOTS more widely and stop TB.'

For more information, please contact Gregory Hartl, WHO, Geneva on +41 22 791 4458, Becky Owens, WHO, Geneva on +41 22 791 2630 (cellphone +41 22 79 217 3403/+41 22 79 213 4314), Patrick Bertrand, IUATLD, Paris on +33 1 44 32 0442 (cellphone +33 6 85424387), or Wattana Manaviboon, Ogilvy PR, Bangkok on +662 632 8300.

Top-level meeting at White House on tuberculosis

The following is from a WHO Press Release WHO/79 of 28 October 1998:

Soros, Wolfensohn and Brundtland meet with Hillary Clinton; Urgent action needed to prevent drug resistant tuberculosis strains

Washington – At the invitation of First Lady Hillary Rodham Clinton, Secretary of Health Donna E.

Shalala, the Administrator of the US Agency for International Development (USAID), Brian Atwood, World Health Organization (WHO) Director-General Dr Gro Harlem Brundtland, World Bank President James D. Wolfensohn and financier George Soros met with her at the White House this afternoon to discuss possible new initiatives to fight tuberculosis (TB) and prevent the emergence of drug-resistant strains.

It is hoped that such initiatives would mobilize millions of dollars in new funds to accelerate international TB control efforts, the majority of which would go directly to fighting TB in high-burden countries. More international attention to the TB problem is needed if solutions to challenges facing TB control efforts are to be developed. One major challenge is to ensure that effective anti-TB drugs are available everywhere in the world. The DOTS (directly observed treatment, short-course) strategy is recommended by WHO to accomplish this (see background note for full explanation of DOTS). It is also important that new tools be developed to help in the eventual elimination of TB.

Currently, TB is the single biggest infectious killer of youth and adults, causing between 2 to 3 million deaths each year. Increasingly, TB is appearing in forms resistant to multiple drugs (MDR-TB) that cannot be cured by once-effective medicines.

In October 1997, WHO warned of the emergence of multidrug-resistant 'hot zones' around the world, where TB could become incurable for anyone who does not have access to the most sophisticated and expensive healthcare. MDR-TB raises treatment costs 100-fold – up to US $250,000 per patient in industrialized countries – and greatly reduces the chances of survival.

A three-pronged strategy will be used to stop drug-resistance. First, to help countries expand their use of DOTS, thereby ensuring that powerful anti-TB drugs are taken properly. This has been shown to prevent the emergence of MDR-TB in Korea, Algeria, Chile, Tanzania and New York City. Second, to increase research into implementing an enhanced version of DOTS, known as 'DOTS Plus', that can treat existing drug-resistant cases. And third, to develop a long term vision for TB research that can develop new tools to one day completely eliminate the threat of TB.

Without increased funding for and political commitment to the fight against TB, WHO estimates that over 200 million people alive today will become ill with the disease.

For further information, journalists can contact Gregory Hartl, Health Communications and Public Relations, WHO, Geneva. Telephone (41 22) 791 4458. Fax (41 22) 791 4858. Email: hartlg@who.ch

Tropical Medicine Resource: The Wellcome Trust, London, UK

The following appeared in *TDR News*, *57*, October 1998:

The association between TDR and the Wellcome Trust is an ongoing relationship of cooperation and collaborations: a fruitful partnership.

The Wellcome Trust has had a long history of involvement in tropical medicine, driven by the active interest of its founding father Sir Henry Wellcome. Sir Henry's experiences in the tropics strongly influenced his pharmaceutical company and his philanthropic activities—the establishment of the Wellcome Laboratories in the Sudan being a prominent example. Since his death in 1936, the Wellcome Trust has actively supported tropical medicine research—with overseas units in Kenya, Thailand and Vietnam. Today those units play a critical role in enabling high quality clinical and epidemiological field research of practical medical importance and in providing training for local scientists.

The main focus of the Wellcome Trust is in funding biomedical research—it is currently spending some US$ 350 million on research every year. As a not-for-profit charity, free of any commercial imperatives and independent of government, the Trust can pursue its philanthropic objectives from a balanced rational long-term perspective, but always informed by the guiding principle that it should support 'scientific research which may conduce to the improvement of the physical conditions of mankind'.

In common with many organizations working within the sphere of tropical medicine, the Trust has

taken an active interest over the past year in the growing problem of malaria and its control. In association with TDR, the Trust has been closely involved in the global collaborative effort to address the resurgent problem of malaria in Africa—the 'Multilateral Initiative on Malaria'. A series of high-profile meetings have taken place—the first being held in Dakar, Senegal—to identify priority research areas and to address the issue of strengthening research capability in Africa. The Trust was pleased to be able to host the London-based meeting of the group in October of last year.

The aim of the initiative is to promote increased interaction and coordination between the range of agencies involved in malaria research or control. It is hoped that tighter coordination will help to prevent duplication of effort and will optimize the investment of resources in priority areas. A further aim is to ensure that effective mechanisms are in place for research findings to be applied. Communication, cooperation and dissemination of information and training strategies are key to the success of any initiative of this type.

An important aspect of the Trust's involvement in Tropical Medicine is within the world of education and training. The Tropical Medicine Resource is a department of the Trust specializing in the creation of training materials aimed at healthcare professionals, whether they be medical students, lecturers, fully qualified practitioners on on-the-ground field staff. This development of training materials is one area where the close links between Wellcome and TDR become immediately apparent.

The largest asset of the Tropical Medicine Resource is a huge archive of visual material—mainly photographs—amounting to some 45,000 images and covering many aspects of tropical medicine. These images are in the process of being catalogued and digitally stored, so that they can be accessed by the outside world—particularly the academic, research and scientific publishing communities. It is of course essential that the images are accompanied by a properly researched, scientifically rigorous and informative description—a job which is done by an in-house team of medically literate writers and editors.

Earlier this year the Tropical Medicine Resource launched four CD-ROM based training products in the series Topics in International Health. The disks contain tutorials, a supporting photographic image collection and an electronic glossary of terms; and cover the following—malaria, trachoma, sexually transmitted diseases and sickle cell disease. Four more disks are planned for later in the year—leprosy, tuberculosis, schistosomiasis and diarrhoeal diseases. The series is intended for use within both the developed and developing world, where the installation base of computers, equipped with CD-drives is growing steadily.

The disks are a testament to the effectiveness of the cooperation and informal partnerships that exist within tropical medicine training and research communities. Written by a team of in-house medical writers, the tutorial contents of the disks are carefully planned by subject experts working in collaboration with the writers. In this aspect the Trust has worked closely with TDR and CTD staff and is indebted to TDR for the many illustrations that they have been able to provide for this purpose. Photographs, graphics and animations are selected to best illustrate the tutorials' content. Readers of the June 1998 issue of TDR News may recall that, as a result of this collaboration, 15 people awarded MIM grants in February have all been sent a complimentary copy of the Topics in International Health Malaria disk.

Future projects covering all aspects of diseases of the poor will involve even closer collaboration, with the Wellcome Trust and TDR working together to provide effective and timely training materials and health information linked to WHO eradication and control initiatives. In so doing, we will be supporting the mission of both organizations—that of helping to improve standards of world health.

Author: Chris Coyer, Tropical Medicine Resource, The Wellcome Trust, 210 Euston Road, London NW1 2BE, United Kingdom. Tel 0171-611-8888. Fax 0171-611-8545. E-mail: publishing@wellcome.ac.uk

Human genome project to complete ahead of schedule

The following appeared in the *British Medical Journal*, *317*, 26 September 1998:

The human genome project is all set to present the fully sequenced human genome in 2003, two years

earlier than expected. A draft version of the genome which should contain up to 90% of the total genetic information, is expected to be ready by 2001.

The human genome project is an international collaboration of research, and the intention of the project is to map out the entire genetic blueprint (genome) of the human being. The benefit of sequencing the entire human genome is that it will give scientists a complete molecular understanding of human beings, and the genetic basis from which humans have evolved, in addition to helping scientists understand what happens when something goes wrong or when diseases interfere with normal functioning. It will also provide pharmaceutical companies with new therapeutic targets.

The draft version of the genome will contain relatively raw information. It should hopefully contain, however, the genes that are generally considered most important to biologists and scientists in a fully sequenced and therefore useful form.

The collaboration involves Britain (which is doing about one third of the work), the United States (which is doing about two thirds of the work), and France, Japan, and Germany (which are making small contributions). In Britain, the bulk of the DNA sequencing is being carried out at the Sanger Centre in Cambridgeshire. In the United States, the main centres are the University of Washington, the Whitehead Institute at Harvard University (Cambridge, MA), the University of Houston, and the University of Oklahoma. Funding in Britain comes from the Wellcome Trust and the Medical Research Council. In the United States, most of the funding is from the National Institutes of Health, which set up the National Human Genome Research Institute in Bethesda in Maryland, and the Department of Energy. Work in both continents began in 1990, but sequencing began in earnest in 1992.

The project's overall planning and direction has been an evolutionary process, with the division of labour being discussed and allocated at a series of international meetings. For example, sequencing work on some genes is going on in both Britain and the United States, whereas others are being sequenced only by one centre. It is possible to identify which laboratory is working on a particular gene by looking at the human genome index, a web based tool set up by the National Center for Bioinformatics. Each participating centre has agreed not to take a stand on intellectual property.

Each day short sections of DNA (which are a minimum of 2000 nucleotides long) are sequenced. These short sections are then pieced together into larger fragments. Once the accuracy of these larger fragments is confirmed, they are released into public databases. To date, about 6% of the human genome has been completely sequenced and assembled, with 12% more of it available in rough draft form.

Apart from the basic sequencing of the genome, and the plan to study human genetic variation and human susceptibility to disease, the project is also sequencing the genomes of other important organisms. These include the mouse, yeast, the fruitfly, the Japanese puffer fish, and the roundworm (due to be completed by the end of 1998).

The mouse is of particular interest because of its genetic similarity to humans. By identifying in the mouse the genes that are important for the regulation of other genes, it will be possible to go back to the human genome and identify sections of DNA that are likely to have a similar role in humans.

A further part of the project is designed to study the ethical, legal, and social implications of genome research (this will include the linking of genetic information with personal identity, race, and religion). The database will also be useful for those involved in developing new biological technology. Such developments will include looking for ways to compare the genomes of a large number of individuals to identify disease susceptibility and contraindications to drugs.

The project is now expected to be completed two years ahead of schedule because of advances made during the past few years with the technology used to sequence DNA and because the costs of running this sort of technology have come down.

Earlier this year Dr Craig Ventner, one of the scientists who had been participating in the human genome project, announced that he was breaking away from the project but would be pursuing the same goals from his own Maryland based company (23 May, p. 1558). Dr Ventner said that he could sequence the human genome much more rapidly and at lower cost than the federal project. Fears that this

announcement would lead to US funding being withdrawn from the human genome project seem to be unfounded.

WHO Global Buruli Ulcer Initiative

The following is taken from a poster produced (1998) by this Initiative:

10 Facts about Buruli Ulcer

1 Caused by *Mycobacterium ulcerans*.
2 Although the true burden is unknown, it is considered the third most common mycobacterial infection of immunocompetent humans after tuberculosis and leprosy.
3 Mode(s) of transmission not entirely known.
4 Most patients are children who live in rural areas near rivers or wetlands.
5 Starts as painless swelling in the skin.
6 Often destroys massive areas of skin and sometimes bone, causing deformities and disabilities.
7 Most commonly afflicts extremities of the body.
8 Current treatment is surgical excision requiring long hospitalizations.
9 HIV infection is not a known risk factor.
10 Early detection and treatment prevent complications.

Recognizing Buruli ulcer as an emerging public health threat, the World Health Organization has established the Global Buruli Ulcer Initiative to coordinate control and research efforts world-wide.

A Buruli Ulcer Task Force was established in 1998 to guide the organization's work related to the disease. Through technical support to endemic countries, the initiative seeks to:

- assess local health services and resources currently available for the diagnosis and treatment of Buruli ulcer in endemic areas;
- strengthen the capacity of health systems in endemic areas by upgrading surgical facilities and improving laboratories;
- strengthen surveillance systems in collaboration with other disease control programmes such as those dealing with tuberculosis, leprosy and Guinea worm to increase early detection and referral for treatment;
- improve health education and staff training in communities most affected;
- stimulate essential research on toxin and vaccine development, drug development, rapid diagnostic methods, environmental changes that favor the emergence of the disease, and the global burden of the disease.

Because of the difficulty in accessing health services in endemic areas, patients often seek treatment late in their illness, and complications are frequent and severe. Consequently, hospitalization is prolonged and the treatment per case consumes more resources relative to other diseases. With an increasing number of cases and the associated complications, the long-term socioeconomic impact of Buruli ulcer on rural economies could be substantial. Furthermore, the disease could seriously undermine the efficient use of scarce health resources in endemic countries.

Advocacy is a critical component of the initiative because little attention has been paid to Buruli ulcer in the past. WHO seeks to develop partnerships with NGOs to assist endemic countries and mobilize the resources necessary to help end the suffering associated with this disease.

For more information on the initiative, contact Dr Kingsley Asiedu, WHO Global TB Programme, CH-1211 Geneva 27, Switzerland. Phone (41 22) 791 2803. Fax (41 22) 791 4199. E-mail: Asieduk@who.ch.

See also: Report—International Conference on Buruli Ulcer. Control & Research. Yamoussoukro, Côte d'Ivoire, 6–8 July 1998. WHO/TB/98.252.

New HIV strain may be resistant to drugs

The following is taken from the *British Medical Journal 317*, 11 July 1998, page 100:

The best available antiretroviral drugs, including protease inhibitors, may lose their potency against HIV because new strains of the virus resistant to the strongest drugs have already emerged.

A team of AIDS researchers has reported a case in which a person has become infected with a strain of HIV that is resistant to six of the 11 approved antiretroviral drugs for HIV, including protease inhibitors. Protease inhibitors have been approved for two years; used as part of triple combination therapies, they have contributed to a dramatic decline in death rates from AIDS. Protease inhibitors work by blocking the construction of proteins considered pivotal to replication of the virus.

Transmission of drug resistant HIV strains has been reported previously, but only to antiretrovirals known as reverse transcriptase inhibitors, which work by blocking replication of the virus. These have been used for 10 years but are considered to be less effective than protease inhibitors. This is the first time a strain resistant to protease inhibitors has emerged. The team of researchers that made the discovery announced its findings at the 12th world AIDS conference in Geneva last week. Research results will also be published shortly in the *New England Journal of Medicine.*

The subject of the case study was a middle aged, homosexual man who reported that the only risk encounter he had had in the six months before he was found to be infected with HIV was receptive anal intercourse without a condom. He said that his partner had withdrawn before ejaculation, a behaviour that many homosexual men have considered to be a low risk practice.

Dr Frederick Hecht, head author of the study, said that he is concerned that there may be a tendency toward complacency because of the success of available treatments. 'But the fact that this transmission occurred by a practice that many consider to be safe highlights the crucial role of continued prevention efforts,' he said. In this case, evaluation of the partner's virus showed many of the same mutations, while other genetic tests showed that the virus in the patient closely matched that of his partner.

This case of resistance 'shows that we can do more harm than good if we don't help patients take their medications correctly,' said Margaret Chesney, professor of medicine at the University of California in San Francisco and a coinvestigator in the study. Dr Chesney said: 'The bottom line is that helping patients stick to these difficult regimens is as important as the drugs themselves.'

In a separate study presented at the world AIDS conference, researchers found that many people among San Francisco's HIV positive urban poor population did not adhere to the strict drug regimens prescribed for them, and only 8% were receiving protease inhibitors. The research project, called the REACH (Research in Access to Care in the Homeless) study, was started following concerns that urban poor populations may develop resistant strains of HIV as a result of poor compliance with their treatment. The researchers found that average adherence was 80% by pill count, with adherence being highly correlated to viral load. Small amounts of missed drugs translated into large effects on the amount of virus in the patient's blood.

Carriage rates and fetomaternal transmission in infections due to hepatitis B & C

The following commentary appeared in the *British Medical Journal 317* of 15 August 1998, page 440:

Hepatitis C virus was identified in 1989 in the United States. Parenteral and sexual transmission is responsible for most hepatitis C infection worldwide. There is a difference in carriage rate between hepatitis B and C. For example, over 80% of people infected with hepatitis C virus become chronic carriers compared with up to 20% of those infected with hepatitis B virus.

One possible explanation for this difference between the two viruses is that hepatitis C evades the immune system more easily than hepatitis B because it mutates more rapidly. This theory is supported by the observation that one person may be infected by several subtypes of hepatitis C simultaneously. Vaccine development will prove difficult for the same reason.

Fetomaternal transmission of the two viruses also differs. In mothers infected with hepatitis B virus the vertical transmission rate may be over 90%. The immaturity of the neonatal immune system at least partly accounts for this inability to mount an immune response sufficient to clear the virus. With hepatitis C virus, however, which has recently been shown to be present in the uterine muscle as well as in blood, vertical transmission is only about 6% (but higher if the mother is HIV positive).

Information famine hits Kenya's healthcare

The following is from the latest issue of *INASP Newsletter*. No 11, November 1998 (INASP, PO Box 2564, London W5 1ZD, United Kingdom):

Kenyans have been told that their country's health providers could be employing obsolete treatment procedures due to lack of current medical journals. AMREF's director general, Dr Erik Nordberg, said doctors and other medical personnel relied on old notes acquired from their basic training, as they had no money to procure current literature. Speaking at an international conference organised by the *East Africa Medical Journal*, he said health workers could not provide quality services if they were inadequately informed.

He presented the findings of a study of clinical officers, nursing officers and public health officers in Makueni district, who were using information gained from basic training over ten years ago and lacked current information on drugs and technology. Dr Nordberg said the situation was aggravated by lack of libraries in hospitals and health centres. Ways had to be found to make books and journals available at affordable prices.

EAMJ Editor, Professor Bill Lore, lamented that plagiarism was mushrooming, and that many doctors were reluctant to write for journals. Dr Khama Rogo, chairman of the Kenya medical association said many doctors were also reluctant to read! He urged that doctors in remote parts of the country be provided with pagers and mobile phones and be connected to the Internet.

Professor Peter Odhiambo, former Dean at the University of Nairobi Faculty of Medicine, agreed the University medical library was poorly stocked due to the high cost of books. Students, he said, could not afford to buy books or subscribe to journals. Paul Chuke, WHO country representative, told the conference that medical developments in healthcare 'render most of the information we acquired in medical schools elementary'.

The author, Ogeke Araka, is a freelance journalist in Kenya. A short version of his report has appeared in Africa Health*, FSG MediMedia Ltd, Vine House, Fair Green, Reach, Cambridge CB5 0JD, UK.*

WHO: Essential Drugs Monitor

The Essential Drugs Monitor is produced and distributed by the WHO Action Programme on Essential Drugs. It is published in English, French, Spanish and Russian, and has a global readership of some 200,000 to whom it is free of charge. The Monitor carries news of developments in national drug policies, therapeutic guidelines, current pharmaceutical issues, educational strategies and operational research.

WHO's Action Programme on Essential Drugs was established in 1981 to provide operational support to countries in the development of national drug policies and to work towards the national use of drugs. The Programme seeks to ensure that all people, wherever they may be, are able to obtain the drugs they need at the lowest possible price; that these drugs are safe and effective; and that they are prescribed and used rationally.

All correspondence should be addressed to: The Editor, Essential Drugs Monitor, World Health Organization, CH-1211 Geneva 27, Switzerland. Fax: +41 22 791 4167. E-mail: DAPMAIL@WHO.CH

INASP-Health, Oxford, UK

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

The network currently involves more than 500 participants, North and South, representing non-governmental organizations, international agencies, library services, publishers (print and electronic), and others. Visit our web-site at http://www.oneworld.org/inasp/ 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, INASP, 27 Park End Street, Oxford OX1 1HU, UK.

Leprosy patients sue Japanese government

Thirteen former leprosy patients in Japan are suing the government on the grounds that the country's isolation policy violated their constitutional right to happiness. As reported in a recent issue of *The Lancet*, the former residents in leprosaria also accuse the government of negligence in failing to rehabilitate them promptly after the discovery of an effective treatment. Under a fierce quarantine policy established in 1907, people with leprosy were forced to live in remote leprosaria; men who wished to marry had to have vasectomies and pregnant women were forced to have abortions. Many countries had comparable policies but this situation lasted longer in Japan than elsewhere, and there was no real reform until 1996. A former health minister then formally apologized for the prolonged existence of outdated regulations which, he said, 'wounded the dignity of the victims and their families and caused them great suffering.' But the authorities sidestepped any mention of legal responsibility, according to *The Lancet*. The 13 who have started a lawsuit claim that it will be impossible to dispel the social prejudice against former patients as long as the government maintains an ambiguous legal position on whether its policies were mistaken.

Source: LepNews, Vol 7, No 2, October 1998, Action Programme for the Elimination of Leprosy, CH-1211, Geneva 27, Switzerland.

FDA in USA approves new anti-tuberculosis drug

The *British Medical Journal, 317*, 4 July, 1998, page 11 reported as follows:

The US Food and Drug Administration has approved rifapentine (Priftin)—the first new antituberculosis drug to be licensed in 25 years.

Rifapentine is indicated for pulmonary tuberculosis but must be used in conjunction with other antituberculosis drugs. It is expected to increase patient compliance because it has a shorter treatment course than conventional drugs.

Current treatment regimens for active pulmonary tuberculosis require a minimum of 6–9 months of treatment with at least three drugs, which usually include isoniazid, rifampicin, and pyrazinamide. Treatment can last over a year in recalcitrant cases. Because the regimen is complicated and lengthy, patient compliance is problematic and treatment errors are common. These factors contribute to the emergence of multidrug resistant strains of tuberculosis.

Like rifampicin, rifapentine is given twice a week for two months in the intensive first phase of treatment when daily isoniazid, pyrazinamide, and ethambutol are also required. However, in the next four months of treatment, one dose of rifapentine once a week is sufficient, as opposed to a twice weekly dose of rifampicin. Although this regimen still seems complicated, it is expected to increase compliance and reduce costs associated with directly observed treatment.

Clinical studies on rifapentine in which the drug was substituted for rifampicin in combination therapy showed that the drug was associated with a higher relapse rate than standard treatment, with 10% of patients taking the rifapentine combination relapsing, compared with 5% taking rifampicin. However, this higher relapse rate is expected to be offset by greater compliance.

The United States is the first country to approve rifapentine, but the largest market for the drug is likely to be in developing countries—however they may be unable to afford it.

Bees for development

Bees for Development promotes sustainable beekeeping practices world-wide and serves as a unique, international resource for beekeeping development.

Its aim is to assist people living in poor and remote countries of the world by providing information to improve their beekeeping knowledge and skills, and as a result enhance their standard of living with an increase in crop yield, a better diet, and income from the sale of bee products.

Bees for Development:

- Supports beekeepers in developing countries
- Promotes sustainable simple beekeeping
- Publishes the award-winning journal *Beekeeping & Development*
- Organises training courses
- Plans, designs, implements and evaluates projects
- Gives expert advice

Bees for Development is an independent, not-for-profit organisation founded in 1993 by Dr Nicola Bradbear and Ms Helen Jackson.

For more information contact: *Bees for Development, Troy, Monmouth NP5 4AB, United Kingdom. Tel: +44 16007 13648, Fax: +44 16007 16167, E-mail: busy@planbee.org.uk, WWW:http://www.planbee.org.uk*

Badgers in the UK 'guilty by suspicion' of spreading bovine TB to cows

'From deliberate culling to accidental death on the road, humans have had a major impact on the badger population. Farmers, for example, convinced that badgers spread tuberculosis (TB) to cattle, demanded their slaughter. An outcry from animal conservation groups followed and, in 1992, laws protecting badgers were introduced. Since then, the badger population in the UK has made a remarkable recovery. Unfortunately, TB in cattle has also increased. Over the last ten years, the incidence of TB has risen steeply in south-west England and the disease is now spreading north into Hereford and south Wales.

Eliminating bovine TB is not only in the farmer's interest—human health can also benefit. Before the 1930s, 10 per cent of human TB came from cows. Since then, pasteurization of milk and the compulsory slaughter of all infected cattle has limited the spread of the disease.

Although badgers are a wild-life reservoir of TB, there is no hard evidence linking them with outbreaks in cattle. The relationship is circumstantial. 'In the areas where cows are infected, if you test the local animals, you find a high incidence in badgers' says Douglas Young of Imperial College School of Medicine. And, in areas where badgers were removed, the number of outbreaks did go

down. 'Though it does seem likely that badgers are the problem, this is not conclusive proof,' he adds.

Last autumn, a panel led by zoologist John Krebs outlined an experiment that will, once and for all, determine whether badgers spread TB to cows (though since the work could take five years to complete, the committee also recommended investment in new research to develop vaccination strategies for control of bovine TB). The plan is to take 10 km square 'hot spots', where the frequency of TB in cattle is high, and implement three different strategies: no intervention, culling all badgers, and removing badgers only after an outbreak of TB in cattle. The effects of such strategies on the spread of TB should determine whether badgers are guilty as charged or innocent bystanders.'

Source: Wellcome News Issue 15, Q2, 1998. The Wellcome Trust, 210 Euston Road, London NW1 2BE.

Private doctors in India prescribe wrong tuberculosis drugs

The following, by Ganapati Mudur, New Delhi, appeared in the *British Medical Journal*, *317*, 3 October 1998, page 904:

Many private doctors in India are violating tuberculosis guidelines by giving their patients wrong combinations and inappropriate doses, a study has found. This may be a factor contributing to the rise of multidrug resistant tuberculosis in India.

The Indian health ministry's tuberculosis control programme detects 1·5 million new cases a year, but tuberculosis still kills around 1200 people each day. The study, conducted by a government tuberculosis centre in Maharashtra state, found 71 faulty prescriptions among a set of 100 issued by doctors possessing a postgraduate degree in medicine (*Indian Journal of Tuberculosis* 1998;45:141–3). It found that 60% of prescriptions for rifampicin and 90% of the prescriptions for ethambutol were faulty.

'This is a surefire recipe for drug resistance,' said Dr Mukund Uplekar, a research consultant with the non-governmental Foundation for Research in Community Health in Bombay, which had previously found 90 different combinations among 113 prescriptions by private doctors. 'Many doctors are just not aware that prescribing a single drug in tuberculosis is like a criminal act,' Dr Uplekar said.

'The sample sizes of prescription surveys are small, but the larger picture is even worse,' said Dr Mira Shiva, head of policy at the Voluntary Health Association of India. Thousands of patients across rural India also first approach doctors in practising traditional medicine and even bogus doctors.

The government's tuberculosis control programme is aimed at expanding the World Health Organisation's recommended 'directly observed treatment short course' (DOTS) strategy to cover most of India. But this is expected to take several years. Government officials concede that about half of the patients are exposed to 'several regimens, varying in duration of treatment and levels of efficacy.'

An unpublished study by the Tuberculosis Research Centre in Madras has also sparked concerns about the quality of drugs. The early 1990s study examined fixed dose combination drugs—pills containing fixed doses of two or more antituberculosis drugs—and found that the bioavailability of rifampicin in some samples was unsatisfactory. Fixed dose combinations are intended to lead to better compliance by reducing the number of pills that patients have to swallow.

Tripartite alliance against tropical disease: Wellcome Trust, London, UK

Infectious disease—still the world's major killer—is the target of a new $25 million joint initiative

launched by the Wellcome Trust and the Burroughs Wellcome Fund, an independent US charity. The initiative aims to strengthen the research capacity in the developing world, to provide local researchers with the expertise to understand and tackle the infectious diseases that so blight life in the tropics.

Following a meeting held at the Cho Quan Hospital in Ho Chi Minh City, Vietnam, in May 1998, it was decided that the centre of gravity should rest in the developing countries, which bear the major burden of infectious disease. Hence, the award programme is of a tripartite nature—a partnership between researchers in a tropical developing country, the UK, and the USA or Canada. Though a principal investigator in any of these locations may lead an application, the project must include strong collaborative links with the other two areas.

The research programmes will focus on bacterial, viral and parasitic diseases. Research on malaria and HIV, though of paramount global importance, will not be funded as other international programmes are already supporting substantial work on these diseases. The emphasis is on projects seeking to put research into practice, and those addressing practical problems. The scope of the initiative is wide-ranging, encompassing basic studies of disease, studies in public health, epidemiology, diagnostics, therapeutics and vaccine development. The programme's goal is to strengthen the existing research base of developing countries, through collaborations with Western laboratories and by promoting scientific training for local researchers.

Applications forms and a more detailed outline of the scheme can be found on the Wellcome Trust Web site (www.wellcome.ac.uk), or by contacting Seam Hussain at the Wellcome Trust (E-mail: s.hussain@wellcome.ac.uk) or Dr Victoria McGovern at the Burroughs Wellcome Fund (E-mail: vmcgovern@bwfund.org).

WHO: Drugs Used in Skin Diseases. Model Prescribing Information, 1997

Curable or controllable skin diseases remain common in many rural communities in developing countries, and they have serious health, social and economic consequences. The publication provides model prescribing information for essential drugs used in their treatment, with details of dosage, uses, contraindications, precautions and adverse effects. It includes details of the drugs used to treat parasitic, fungal, bacterial and viral infections of the skin, bites and stings, pigmentary disorders, malignant melanoma and dermatoses among others. Conditions common in children, acne vulgaris, cutaneous reactions to drugs and urticaria are also covered. The diseases included are mostly very common, and prevalent in developing countries, although some rare, life-threatening disorders such as pemphigus are discussed briefly. The emphasis is on giving the basic information necessary to treat skin diseases in the community safely, effectively and at the lowest possible cost. Preventive measures, such as improvements in hygiene, nutrition, housing and sanitation, are also discussed.

The book is part of a series of WHO publications which provide up-to-date and independent clinical information on essential drugs. The information is intended as source material for adaptation by national authorities, particularly in developing countries, that wish to produce drug formularies, data sheets and teaching materials.

Available in English (French and Spanish in preparation), from: World Health Organization, Distribution and Sales, 1211 Geneva 27, Switzerland. Price: Sw.fr.35/US$31.50, and in developing countries Sw.fr.24.50.

Dr Minoo Mehta International Prize 1998

The 1998 awardee of the Dr Minoo Mehta International Prize is Mr Yog Raj Paudel from International Nepal Fellowship – Green Pastures Hospital in Pokhara, Nepal. Mr Yog Raj Paudel, aged 39, is married with three children. In 1979 he started to work at the Green Pastures Hospital in Pokhara.

He started first his career as an office assistant and became assistant administrator in 1985. From 1990 on he was acting administrator and from 1991 on administrative officer of the Leprosy Control Project, Dang in Nepal which is run by the International Nepal Fellowship with the financial and technical support of the German Leprosy Relief Association.

The Dr Minoo Mehta International Prize is named after the late son of Dr and Mrs Dr Jal Mehta, Poona, India. The Prize is allocated as an annual stipend. This is done in appreciation of the leprosy work performed by Dr Jal Mehta and of the mutual cooperation lasting for years as well as in recognition of the support given by Dr Mehta to leprosy relief work in India. The Dr Minoo Mehta International Prize was not allocated in 1997.

Comparative leprosy vaccine trial in South India

This report provides results from a double blind randomized prophylactic leprosy vaccine trial conducted in South India. Four vaccines, viz., BCG, BCG + killed *M. leprae*, *M. w* and ICRC were studied in this vaccine trial in comparison with a normal saline placebo. From about 300,000 people, 216,000 were found eligible for vaccination and among them, 171,400 volunteered to participate in the study. Intake for the study was completed in 2½ years from January 1991. There was not a single serious case of toxicity or side effects subsequent to vaccination for which decoding was required. All the vaccine candidates were safe for human use. Decoding has been performed subsequent to the completion of the second resurvey in December 1998. Results for vaccine efficacy are based on examination of more than 70% of the original 'vaccinated' cohort population, in both the first and the second resurveys. It was possible to assess protective efficacy of the candidate vaccines against all forms of leprosy together. Observed incidence rates were not sufficiently high to answer the question of protective efficacy of vaccines against progressive and serious forms. ICRC provided 65.5% protection (CI 48.0–77.0), BCG + killed *M. leprae* provided 64.0% protection (CI 50.4–73.9), *M.w* gave 25.7% protection (CI 1.9–43.8) and BCG gave 34.1% protection (CI 13.5–49.8). Protection observed with ICRC and the combination vaccine BCG + killed *M. leprae* meets the requirement for public health utility and these vaccines deserve further consideration for their ultimate applicability in leprosy prevention.

This article has been published in the *Indian Journal of Leprosy*, **70**, 1998.

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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.

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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.

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CONTENTS