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SPECIAL ARTICLE

A look at world leprosy*

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Introduction

In many ways, leprosy is a unique disease. The fear, abhorence and social stigma that was associated with it in the ancient past, and which lingers even to this day, was understandably a reaction to the extremely crippling mutilations it caused for which neither a remedy nor a preventive could be found. Leprosy was the ultimate disease and the leprosy patient the ultimate pariah in practically every civilization, to the extent that in several languages leprosy came to be referred to as the 'big disease'. Leprosy was dreaded not because it killed but because it left one alive. There was simply no hope for the afflicted.

Looking at leprosy today one can see a vastly changed situation. Leprosy is no more the 'Cinderella' of diseases. The average patient does not suffer from the extreme mutilations widely seen in the earlier days. Most patients live in their own communities and, where facilities exist, can be diagnosed, often early, can receive effective treatment and can be cured with no residual disabilities. There is increasing evidence, at least in some parts of the world, that the intensity of the social stigma is decreasing.

In terms of scientific developments, leprosy has made more progress in the last 20 to 30 years than throughout the whole of the preceding human history. Today, it is in the forefront of modern developments in such fields as immunology and molecular biology. However, the most important progress in recent years has been in the field of chemotherapy of leprosy leading to leprosy control through multidrug therapy (MDT).

The problem of leprosy

Because leprosy is a disease with a chronic course there is a general assumption that the leprosy situation everywhere is rather static. This is not true and leprosy is as capable as any other communicable disease of dynamic changes over periods of time, except that the time scale is different. In terms of magnitude of the problem it is difficult to estimate the current number of cases of leprosy in the world. Case diagnosis and definition are not

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always clear or consistent, and the enumeration of cases in many regions of the world is incomplete or irregular. Despite these difficulties, estimates are extrapolated from available data from time to time. The WHO estimates for 1966 and 1976 were 10·8 and 10·6 million cases respectively; prevalence in the early 1980s was estimated to be 10–12 million cases. Although no estimate has been made recently, it is likely that the current global figures are much lower than they were in the early 1980s.

There are several problems with regard to estimating the prevalence of leprosy.[1] Often it is based on information available from limited areas and on registered cases on which estimates of prevalence are made after applying certain arbitrary correction factors.

Most estimates are made on very inadequate information and seem to remain unchanged for years, if not decades. The assumption was that patients who were eliminated, either because of death or because they were cured etc., were replaced in equal numbers by new patients. In many countries the assumption was never verified and neither were the estimated figures adjusted for natural growth of population. In countries where sample surveys or other modified procedures had been employed, invariably the estimates have turned out to be much higher than the original ones. This was partly because of (a) identification of very early cases who are known to have a high tendency for self-healing, and (b) a good number of inactive cases being included which arose from the difficulty in discriminating them from active cases in cross-sectional surveys. In countries where effective leprosy control programmes have been in operation, with reliable periodic surveys, the difficulties in estimating the magnitude of the problem have been less severe.

The second major problem in relation to measurement of the magnitude of leprosy is the definition of a case of leprosy. There is a considerable amount of confusion in the minds of leprosy workers as to what is a case of leprosy and what is the cure or end point of disease. The introduction of fixed duration of MDT has now offered opportunities to make things easier. In relation to leprosy control, we can consider the following four categories of individuals.[2]

1 Those needing chemotherapy or who are under chemotherapy.
2 Those who have completed treatment and require surveillance.
3 Those who have completed surveillance but need care because of disabilities.
4 Those who have completed surveillance and do not need any further attention.

For epidemiological and operational purposes, including computing of prevalence rates, only those who need or who are under chemotherapy should be considered as cases of leprosy. Thus, for purely operational purposes the state of 'cure' is reached once chemotherapy is completed. While individuals under surveillance following chemotherapy would require some kind of active or passive follow-up, they would not be considered as cases. After completing surveillance a proportion of patients may still require care because of their deformities, and again for operational purposes these should not be considered as cases.

Population at risk

Approximately 1320 million people live in 28 countries where leprosy is a serious problem, i.e. the registered prevalence is over 1 case per 1000 persons, and thus may be

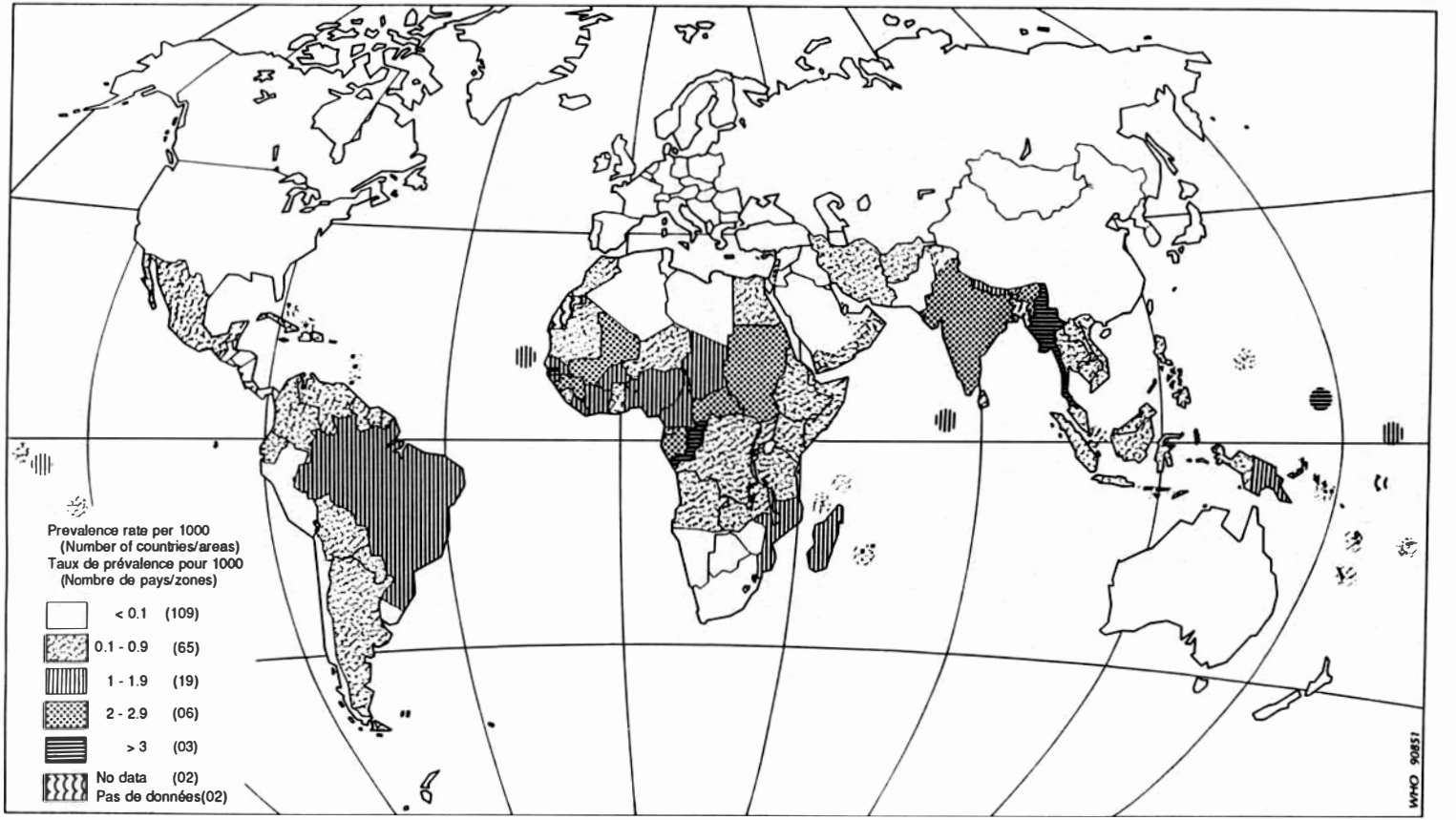

Figure 1. Prevalence of registered leprosy cases in the world, 30 September 1990.

considered as at significant risk of contracting the disease. If one reduces the limit of registered prevalence to 0·1 case per 1000 persons then the number of countries affected would increase to 93 covering a total population of about 2460 million.

Registered cases

Information on leprosy cases registered for treatment is much more reliable than information on estimated cases, as it is based on actual records. There had been a very steady increase in the number of registered cases between 1966 and 1985: 2,831,775 in 1966, 3,599,949 in 1976 and 5,368,202 in 1985. The latter figure represented an increase of 49·1% over 1976, and 89·6% over 1966. The prevalence of registered cases had correspondingly increased from 0·84 cases per 1000 population in 1966 to 0·88 in 1976, and 1·2 in 1985; the geographical distribution of leprosy in 1990 is shown in Figure 1. However, since 1985 there has been a steady decline so that in 1990 the total number of registered cases is 3·7 million, representing a reduction of 30%.

Although information on registered cases appears to be more reliable as it is based on actual records, there are several problems in evaluating this information for the purpose of leprosy control. Firstly, all registered cases are not necessarily under regular treatment whatever the drug regimen. The regularity of treatment varies widely from programme to programme, and often in the region of 50% or so, particularly among patients under dapsone monotherapy. Even among patients who collect their drugs from the clinics, there is a certain proportion who do not consume the drugs as expected. This has been brought out in more than one study on urine checks for dapsone. The next problem in evaluating information on registered cases is that often it is not updated. Inactive cases continue to remain in the registers either because a patient is lost for follow-up or because of the inability to periodically assess the patient's clinical and bacteriological condition. In addition, there are also the problems of duplicate registration of patients in more than one clinic. However, the situation appears to have improved in recent years, partly as a result of the introduction of MDT. This has made it necessary for workers responsible for leprosy control to review their records and to classify patients according to their bacteriological state. In spite of the problems discussed above, the information on registered cases is very valuable for planning, monitoring and evaluating leprosy control activities.

New case detection

Availability of reliable information on detection of new cases in the programmes varies from country to country. From information available to us, the number of new cases detected in 1989 was about 580,000, indicating a case detection rate of about 1 per 10,000 population. A large majority of the new cases were detected in the South-East Asia Region of WHO (85%). When analysed at different levels, the relationship between the number of registered cases and the annual number of new cases detected provides some indication on the effectiveness of case detection activities and the extent of inclusion of inactive cured individuals among registered cases.

The distribution of registered cases, the prevalence rates and the proportion of cases

Table 1. Distribution of registered leprosy cases by WHO regions, 1990*

WHO region	Population—latest official estimate ('000†)	Registered cases	
		No.	Prevalence rate per 1000
Africa	522,475	482,669	0·92
Americas	724,002	301,704	0·42
Eastern Mediterranean	391,460	99,913	0·26
Europe	845,948	7,246	0·01
South-East Asia	1,310,847	2,693,104	2·05
Western Pacific	1,497,539	152,739	0·10
Total	5,292,270	3,737,375	0·71

* Or for the most recent year for which data are available.
† Population data from *World Health Statistics Annual 1988.*

Table 2. Reported registered leprosy cases by WHO region for the years 1966, 1976, 1985 and 1990

WHO region	No. of registered cases			
	1966	1976	1985	1990
Africa	1,685,526	1,398,220	987,607	482,669
Americas	177,813	241,248	305,999	301,704
Eastern Mediterranean	40,963	63,236	74,892	99,913
Europe	19,589	20,452	16,794	7,246
South-East Asia	790,851	1,748,468	3,737,157	2,693,104
Western Pacific	117,003	128,325	245,753	152,739
Total	2,831,745	3,599,949	5,368,202	3,737,375

by WHO Region as of 1990 (or for the most recent year for which information is available) are shown in Tables 1 and 2. Although only a proportion of estimated cases are ever registered for treatment, the information on registered cases reflects, to a large extent, the leprosy situation in any given region and its relative importance *vis-à-vis* other regions.

The number of registered cases by regions has varied over the years, as shown in Table 2 for the years 1966, 1976, 1985 and 1990. However, the information is not strictly comparable over the four years as the number of countries for which information was available has also varied over this period.

The South-East Asia Region, which contributes to the largest share of registered cases in the world, had shown a dramatic increase between 1966 and 1985 with a steep decline in 1990. A large proportion of the cases and changes are in India.

The African Region shows a steady decline in the number of registered cases over the

past two and a half decades. Whether this is due to reduced case-finding activities, to a true reduction, or to both, is not clear.

With regard to the Western Pacific Region, Table 2 indicates a marked increase for 1985, followed by a decrease in 1990. The increase for 1985 is due mainly to the inclusion of information from the People's Republic of China which was not available earlier.

The American Region shows a steady increase in the number of registered cases. A large proportion of this increase is contributed by Brazil.

With regard to the Eastern Mediterranean Region, Table 2 indicates a steady increase over the years. This appears to be largely due to increased case detection.

In the European Region there is a steady decline, the problem itself being quite limited.

Multidrug therapy (MDT)

The last decade has seen several important developments in leprosy and leprosy control. The most important ones were the recognition of the alarming increase in the resistance of *Mycobacterium leprae* to dapsone (both secondary and primary) and the threat this posed to the limited gains made in leprosy control until then, to the availability of more potent

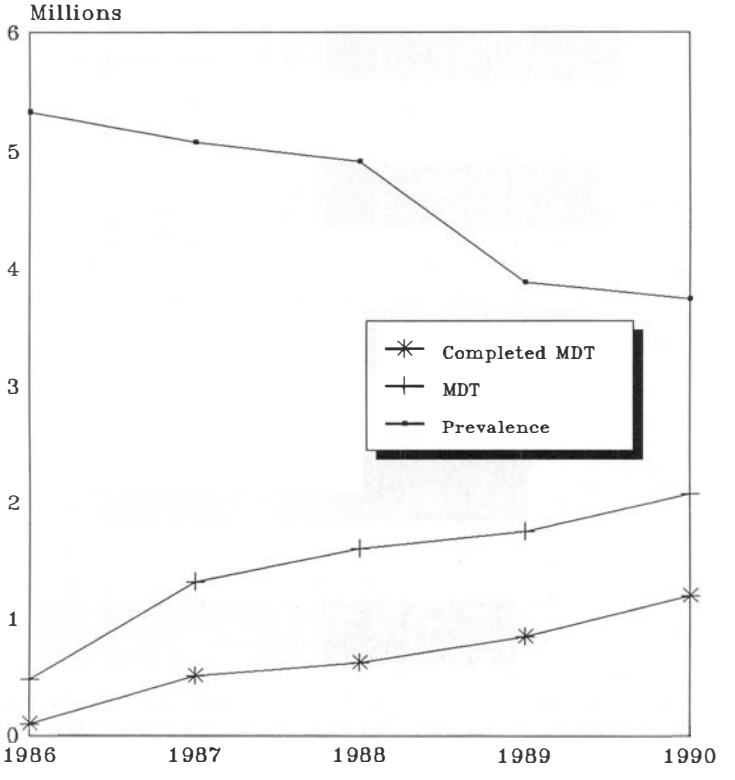

Figure 2. Leprosy prevalence and MDT coverage in the world, 1986–90.

antileprosy drugs and, last but not least, to the recommendations in 1981 of a WHO Study Group on Chemotherapy of Leprosy for Control Programmes to combat drug resistance and to make leprosy treatment more effective and acceptable. The WHO recommendation on MDT is recognized today as a major technological improvement in leprosy control. Indeed, it represents a landmark in the history of leprosy.

With the problem of dapsone resistance increasing in its dimensions, and with the availability of better bactericidal drugs against *M. leprae* such as rifampicin in the 1960s, the application of leprosy treatment through combinations of drugs became a clear possibility. It was realized that with leprosy patients harbouring very large bacillary populations similar to those of tuberculosis patients, successful chemotherapy should be one which was capable of preventing the selection of drug-resistant mutants as well as killing all, or nearly all, of the drug-sensitive organisms. With the selection of drug-resistant mutants being prevented and the killing of nearly all drug-sensitive organisms, it was expected that relapse after stopping chemotherapy could virtually be prevented.

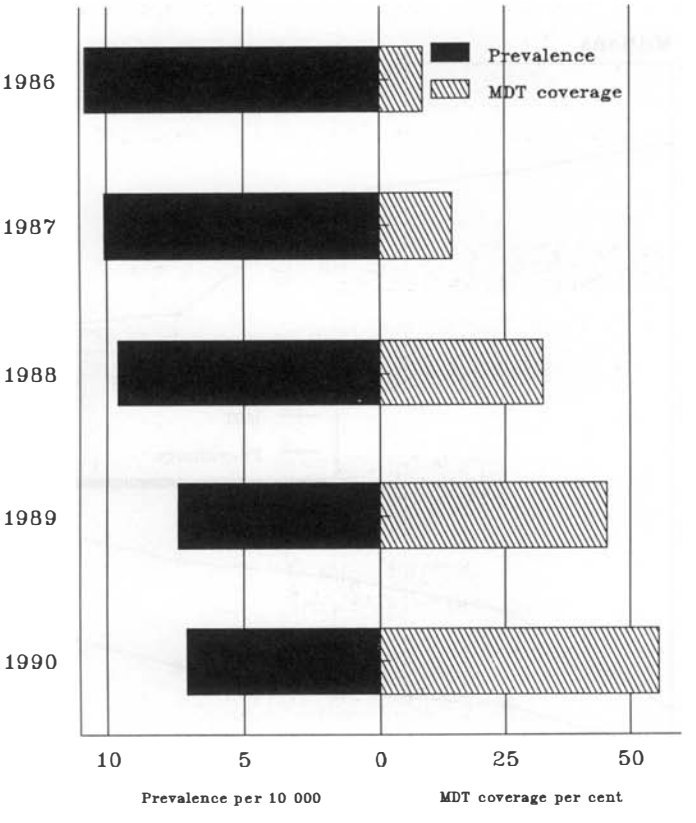

Figure 3. Global leprosy prevalence and MDT coverage, 1986–90.

Recommendations of the WHO Study Group

The standard MDT regimens for paucibacillary and multibacillary leprosy recommended by the WHO Study Group are by now familiar to many health workers.

The recommended standard regimen for paucibacillary leprosy is rifampicin 600 mg once a month for six months, plus dapsone 100 mg daily for six months. The administration of rifampicin should invariably be fully supervised, but dapsone may be given unsupervised.

The recommended standard regimen for multibacillary leprosy is: rifampicin: 600 mg once a month, unsupervised; dapsone: 100 mg daily self-administered; clofazimine: 300 mg once a month, supervised, and 50 mg daily self-administered.

Treatment should be continued for at least two years and, wherever possible, up to smear negativity. In many programmes, dapsone-treated multibacillary patients continue to receive dapsone monotherapy, often for life, even after becoming smear negative. Where resources permit, it is recommended that such patients should be given MDT for two years and chemotherapy should then be stopped. The recommendations were made under very special circumstances which included the urgency of the situation as a result of widespread dapsone resistance, and the need to apply all available knowledge and technology in a practical way. The recommendations were directed primarily towards leprosy control and less towards the individual treatment of patients. Maximum advantage was taken of all available information and operational and cost factors were given due consideration. The Study Group fully realized the limitations of the then available information and recommended more research in relevant areas, and the collection of information on experiences with regard to relapse following completion of MDT.

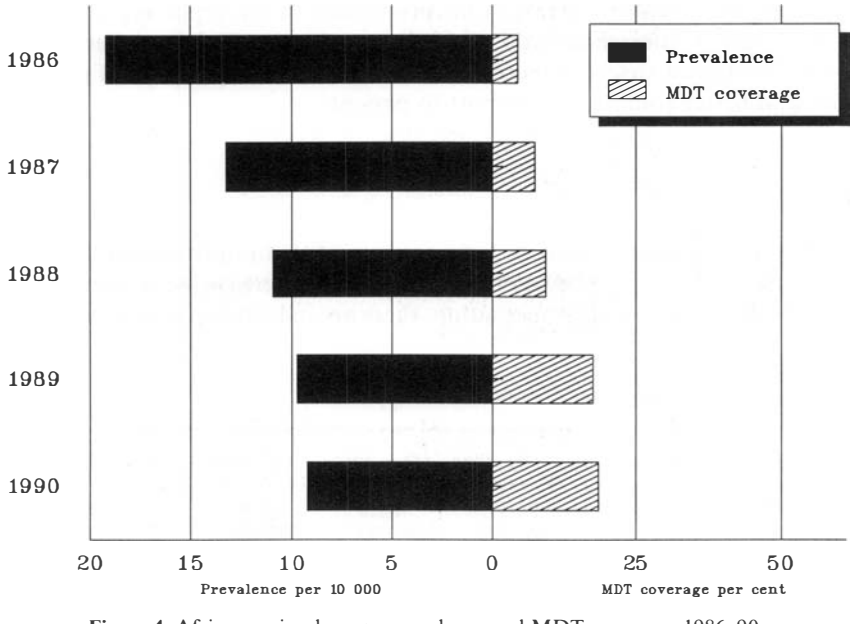

Figure 4. African region leprosy prevalence and MDT coverage, 1986–90.

Acceptance of the recommendations on MDT

The recommendations received enthusiastic support from most of the leprosy-endemic countries, WHO Regional Committees, international and national nongovernmental organizations (NGOs), donor agencies and professional bodies. However, there were problems of acceptance in some countries and projects. These were ultimately resolved largely as a result of positive experiences in areas which had introduced MDT fairly early and through a better understanding of MDT as a public health tool in achieving disease control. Some countries had introduced modifications to the WHO recommended regimens, but these were generally minor and within the essential requirements for MDT. In several countries MDT provided the opportunity to increase the priority for leprosy control and strengthen their political commitments. This was also true for NGOs and donor agencies.

Progress with implementation of MDT

The coverage of leprosy patients with MDT has rapidly increased over the past few years and in September 1990 reached 55·7% of the total registered cases. The increasing acceptability of MDT among national health services and leprosy patients themselves is due to: (a) the fixed, and relatively short duration of MDT treatment; (b) the low-level of toxicity and treatment-related side-effects; (c) the very low relapse rates following completion of treatment (0·12% per year for PB and 0·22% per year for MB based on information from 18,980 PB cases and 9292 MB cases); (d) the high level of acceptance of clofazimine discolouration (0·4% refusal in 31,923 patients); and (e) significant reduction in frequency and severity of ENL reactions. One more advantage of the WHO/MDT regimens is the considerable increase in the proportion of self-reporting cases at an early stage of the disease. Consequently, this has led to a reduction in the number and degree of deformities among new cases; an increased acceptance and compliance of patients to the treatment; and better community support to patients.

MDT coverage

Table 3 and Figures 2 to 8 show the global progress of MDT implementation from 1985 to 1990. For the first time, and in spite of the considerable increase in the number of newly-detected cases during MDT implementation, there are indications of a decline in the total

Table 3. Progress with implementation of multidrug therapy (MDT)

Year	Oct. 1985	Oct. 1986	Oct. 1987	Oct. 1988	Oct. 1989	Sept. 1990
Registered cases (000's)	5,368	5,341	4,813	4,908	3,866	3,737
No. of cases on MDT	78,752	468,222	699,589	1,604,927	1,751,903	2,080,998
% of total cases on MDT	1·47	8·77	14·54	32·70	45·32	55·7
No. of cases who completed MDT (cumulative total)	9,425	93,216	510,593	627,919	853,706	1,204,821

Table 4. Level of coverage for MDT in 93 leprosy endemic countries (prevalence rate of at least 1 per 10,000)

	Countries in WHO regions with MDT						
MDT coverage (%)	AFR	AMR	EMR	EUR	SEAR	WPR	Total
>76	8	12	3	0	4	12	39
51–75	7	2	1	0	3	3	16
26–50	4	4	0	0	2	2	12
11–25	8	1	3	0	0	1	13
1–10	10	0	1	0	0		11
No information	1	0	1	0	0		2
Total	38	19	9	0	9	18	93

number of registered patients in the world. This decline supports the efficacy of the WHO/MDT regimens for leprosy control and opens the possibility of major reductions. However, as shown, the world coverage with MDT for leprosy is very uneven and efforts need to be made to strengthen treatment capabilities in countries and regions where leprosy is endemic.

The coverage of MDT in 93 leprosy endemic countries is given in Table 4. Thirty-nine countries (or 42%) have 76% or more of their registered leprosy patients on MDT, and 55 countries (or 59%) have at least 50% MDT coverage of their patients.

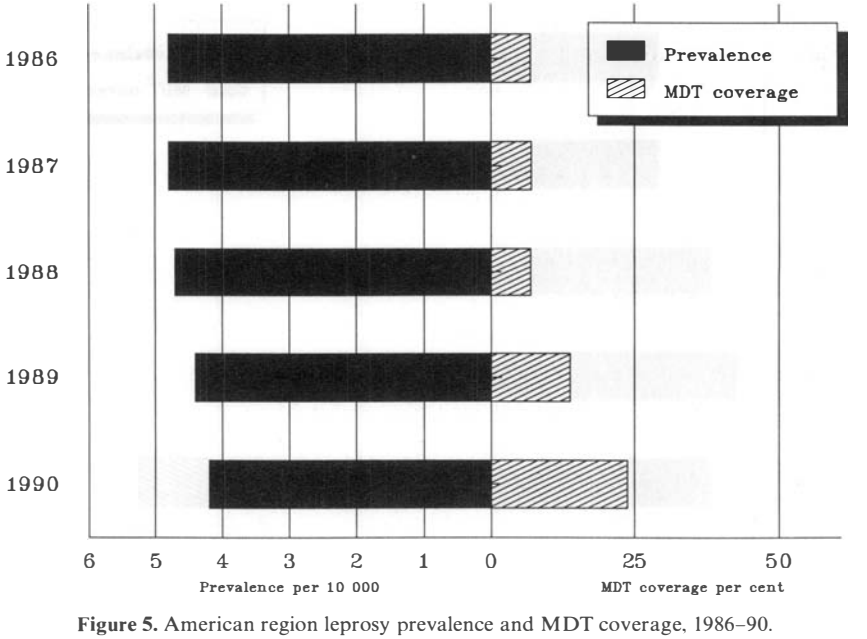

Figure 5. American region leprosy prevalence and MDT coverage, 1986–90.

Positive experiences with MDT to date

Technical

On the technical side the positive experiences include:

(a) the low frequency of drug toxicity in the field;
(b) the high level of acceptance of clofazimine discolouration;
(c) patient satisfaction with clinical response;
(d) the significant reduction in frequency and severity of ENL reactions; and
(e) very low relapse rates after cessation of treatment.

Operational

On the operational side the positive outcomes include:

(a) the marked increase in treatment compliance by patients;
(b) increase in detection of new cases through voluntary reporting;
(c) better motivation among health workers; and
(d) greater community support resulting from the recognition of MDT as effective technology.

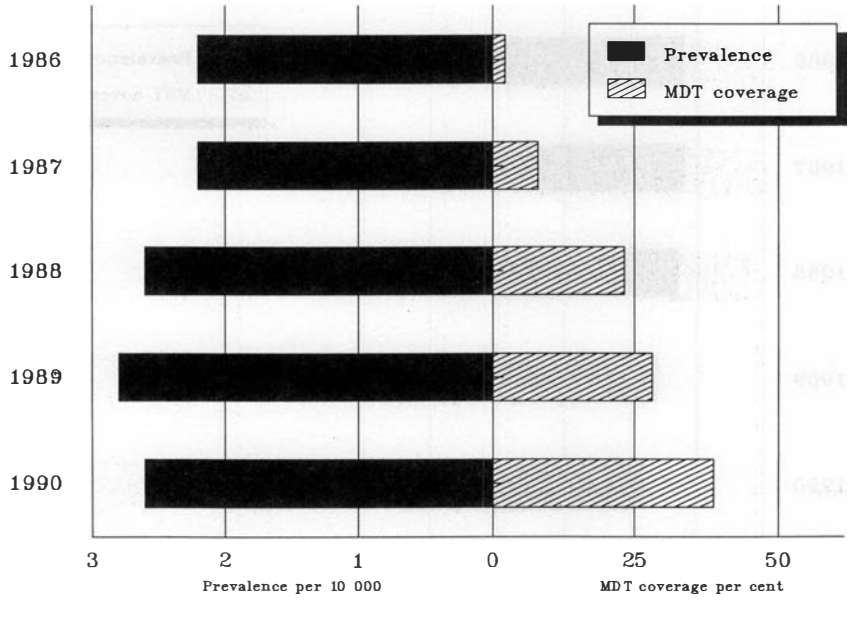

Figure 6. Eastern Mediterranean region leprosy prevalence and MDT coverage, 1986–90.

Problems relating to MDT

Technical

The technical problems experienced so far include:

(a) difficulties in classifying a proportion of patients, partly as a result of inadequate laboratory services;
(b) disappointment with the slow decrease of BI;
(c) slow clinical response following the initial period of very satisfactory response;
(d) difficulties in distinguishing between relapse and late reversal reactions in PB leprosy;
(e) lack of any impact in the deformity situation.

Operational

The operational and administrative problems include:

(a) the inability to increase the priority for leprosy in some countries as a result of other pressing health needs;
(b) poor health infrastructure to cope with MDT;
(c) inadequate resources, particularly for drugs;
(d) absence of a proper plan of action to implement MDT;
(e) inadequate training of health workers;
(f) lack of laboratory facilities for skin-smear examinations;
(g) poor referral facilities to deal with complications; and

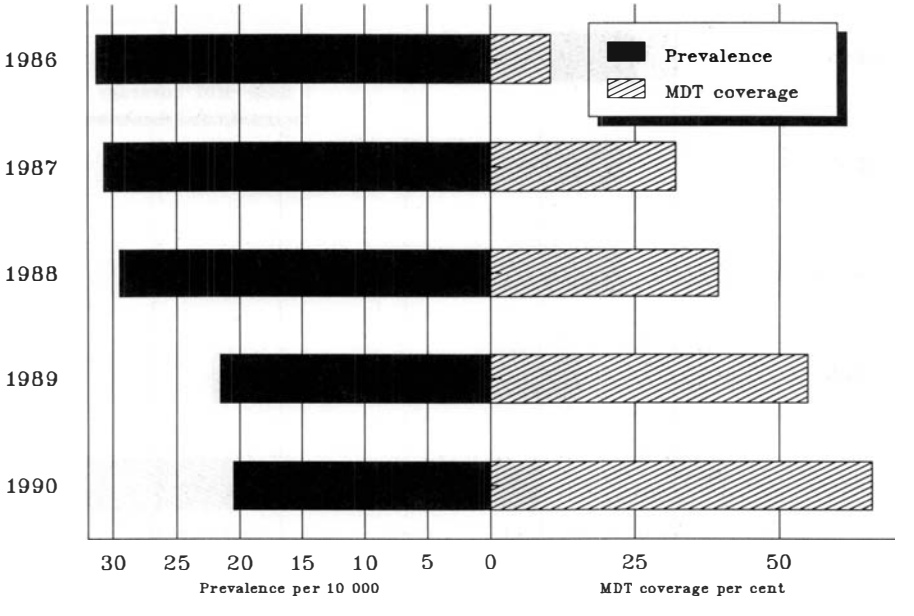

Figure 7. South-East Asian region leprosy prevalence and MDT coverage, 1986–90.

(h) insufficient patient education about what to expect from MDT so that when the time comes for stopping treatment, the decision would be acceptable to the patients.

The need for co-ordination

In spite of the current progress, leprosy control through MDT is facing a number of problems which are slowing its implementation and coverage. The most important ones are: (a) leprosy is often not considered a health priority by governments because the disease and its disability effects are not fully appreciated; (b) in many countries, awareness of and concern for people with leprosy is often restricted to a small number of health professionals (usually those working for voluntary organizations or missions) highlighting the important need for training of health workers at all levels, including district level health managers; (c) the high cost of MDT regimens *vs* dapsone monotherapy; (d) a major constraint in many endemic countries is the poorly-developed health infrastructure as well as the PHC system which make it difficult to reach target populations; and (e) lack of adequate laboratory facilities for skin smear examinations.

However, over the last few years, a few leprosy endemic countries have increased their budget for leprosy control activities, based on the implementation of MDT. In addition, a substantial proportion of funds for the purchase of drugs and related operational costs come from international, bilateral and voluntary organizations, especially the International Federation of Anti-leprosy Associations (ILEP) and the Japan Shipbuilding Industry Foundation (JSIF). Considering the increased need for funds, material and

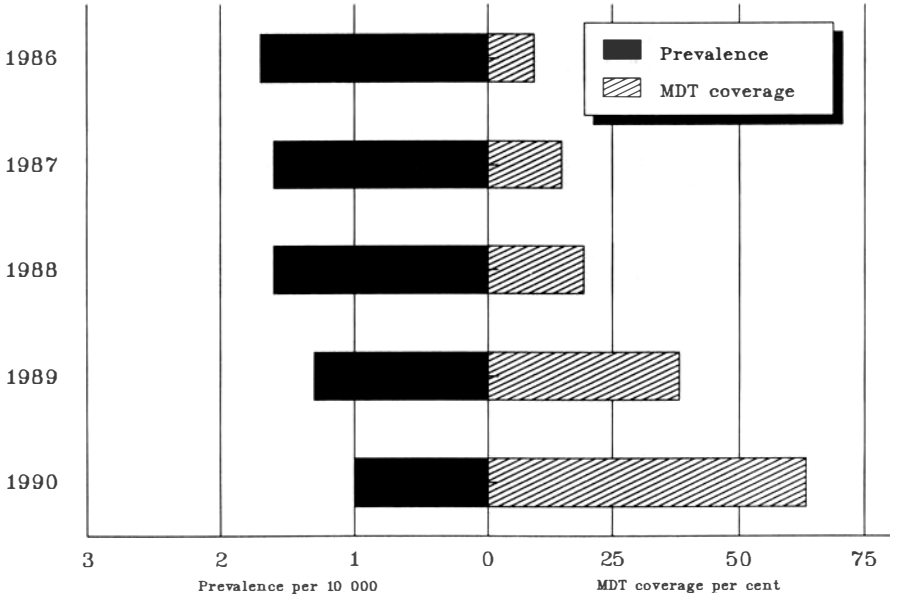

Figure 8. Westen Pacific region leprosy prevalence and MDT coverage, 1986–90.

human resources for a more rapid expansion of MDT coverage, it is important to develop mechanisms for the optimal utilization of available resources at the global, regional and national levels in addition to seeking additional resources. In this respect the WHO Expert Committee on Leprosy in its sixth report strongly advocates effective co-ordination between the national government, national and international non-governmental organizations and other international contributing agencies for optimal utilization of available resources for better leprosy control.

Disability prevention and rehabilitation

Regarding the problem of disability in leprosy, a considerable portion of the disability load is the result of failure to incorporate into leprosy control programmes activities relating to the prevention of disabilities by using simple technologies and patient motivation. While one should admit that current technologies for prevention of deformities are relatively weak, there is no justification for not putting into use what is available.

In spite of all efforts towards early detection and treatment, a proportion of patients will develop deformities and the situation cannot be ignored. Leprosy control programmes are as much medical care programmes as they are programmes for disease prevention, and the prevention and treatment of deformities are part of the medical care. However, we would like to promote rehabilitation based primarily on the involvement of the community, where emphasis will be on the participation of the individual and the family in the rehabilitation efforts.

A major problem confronting control programmes, and one that will continue to confront them for many more years in spite of an increase in the implementation of MDT, is the group of leprosy patients already disabled. It is in this connection that we would like to promote cost-effectiveness approaches such as community-based rehabilitation (CBR).

CBR is a concept closely related to primary health care (PHC). The CBR approach tries to solve the problems in a different way from the institution-based rehabilitation (IBR) hitherto advocated. The CBR approach promotes awareness, self-reliance and responsibility for rehabilitation in the community; builds on manpower resources in the community, including the disabled themselves, their families and other community members, as the disabled and their family members are called on to take an active part in the training efforts; encourages the use of simple methods and techniques which are acceptable, affordable, effective and appropriate to the local setting; uses the existing local organization and infrastructure to deliver services, especially primary health care services, and takes into consideration the economic resources of the country and thus allows for an eventual extension to provide total coverage according to perceived needs.

While there is no doubt that all components of patient care deserve attention, it is important, particularly in the light of resource constraints, that leprosy programmes invest more on those patient-care components that are clearly cost-effective and capable of complementing the implementation of MDT.

Community participation

The participation of the community is highly crucial in several of the activities in leprosy control. This is particularly so in view of the strong stigma against the disease found in many societies. The social problems relating to leprosy, however difficult that may be, can be solved only by facing them squarely and devising appropriate solutions through health education and other measures, and not by evading the issue or by developing cosmetic approaches. Social stigma, severe as it may be in many situations, is often used as an easy excuse for poor performance by health workers in leprosy, when it is quite possible to deal with it in an effective manner.

In most societies, family and community support for leprosy patients does exist, in small measure however, and what is required is to mobilize and strengthen it through community action. It is here that the primary health care approach plays a vital role in disease control which no amount of investment in high technology can replace.

Future prospects

With an increasing political commitment in many countries to deal with leprosy effectively, with the increasing appreciation of the value of MDT as a very potent technology, and with increasing international co-operation, both from the bilateral and multilateral sectors enabling additional inputs, it is not unrealistic to expect a reduction of leprosy caseload by as much as 60 to 80% in the next five to ten years, at least in countries with effective programmes. However, notwithstanding anticipated major reductions in prevalence, it should be recognized that other problems will remain for a long time to come such as disabilities among old cured patients and a continued, albeit reduced, incidence of new disease arising from infections caught several years earlier. Hence, apart from investing heavily on efforts to reduce leprosy prevalence through MDT, there is a need to plan for the future so that leprosy control becomes part and parcel of primary health care encompassing early detection, treatment, as well as disability prevention and management.

References

1 *A guide to leprosy control*, 2nd ed., WHO: Geneva, 1988.
2 WHO Expert Committee on Leprosy. WHO Technical Report Series No. 768, 1988.