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Estimating the size of the leprosy problem: the Bangladesh experience

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Summary Assessing the size of the leprosy problem in a country is an important but difficult issue for the purpose of programme planning. Different methods have been proposed but often estimates have proved to be very different from reality. We have attempted to address this issue in Bangladesh, a country where official estimates are more than 5 times greater than the registered number of leprosy cases.

A combination of methods, including surveys, data from leprosy control programmes and local knowledge based on the Delphi technique have been combined to construct an estimate of the total number of cases in Bangladesh. This figure (173,196) is only 10% greater than the official estimate (136,000). It will be possible over the next few years to see how close this figure is to reality through data obtained from the National Leprosy Control Programme which is now rapidly developing to cover the whole country.

Introduction

Accurate estimation of the size of the leprosy problem is a global as well as national issue. In the past estimates have been shown to be highly inaccurate, particularly when random sampling methods have been used. This has been due to the clustered pattern of the distribution of leprosy as well as to the operational problems of defining a case for survey purposes. We have attempted to combine a number of different methods to produce an estimate for Bangladesh, an approach which may be applicable to other countries.

According to the WHO report for 1994, the estimated number of leprosy patients in Bangladesh is 136,000.[1] This makes Bangladesh third on the list of leprosy endemic countries of the world, after India and Brazil. The leprosy problem is taken seriously and in November 1993 a national project was introduced by the government of Bangladesh for 'Further Development of TB and Leprosy Control Services'. The aim is to strengthen TB and leprosy control services in an integrated programme and, as far as leprosy is concerned, make MDT available in all districts of the country by 1995.[2] Although leprosy control activities, both by government and nongovernmental organizations

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(NGOs), have been going on for many years in some parts of the country, there are hardly any studies available on the extent of the leprosy problem. It is therefore important for planning purposes for this new leprosy control initiative to produce an accurate estimate of the size of the problem.

In a review article from 1945 entitled 'Leprosy in Bengal',[3] it is mentioned that leprosy was most common in the western area (now West Bengal in India) with prevalence rates of 10–30 per 1000, followed by the central and northern districts with a prevalence rate of 5–9 per 1000. The lowest rates (less than 5 per 1000) were indicated to be found in the low lying delta districts of south-east Bengal (the present Bangladesh). In 1965 the prevalence rate in East Pakistan (now Bangladesh) was put at 1·3 per 1000, with a total number of estimated cases of 150,000.[2] In a report of the World Bank of 1990, a prevalence rate of 2·5 was postulated, amounting to 275,000 leprosy cases.[4] This figure was largely based on known prevalence rates in the neighbouring countries and not on specific studies within the country. The currently quoted figure of 136,000 is essentially based on the original figure of 1965, minus the number of cases reported to have completed Multidrug therapy (MDT).

From experience it is known that leprosy is highly endemic in the north-western area of Bangladesh (the Rajshahi Division). This paper reports on surveys conducted in 1993 in 4 districts of the Rajshahi Division, combined with expert opinion from the other divisions of Bangladesh. The objective was to establish more accurately the size of the leprosy problem in order to implement adequate control activities. On the basis of these figures an estimation is made of the prevalence of leprosy in Bangladesh.

Methods

Surveys were conducted in Panchagar, Thakurgaon, Nilphamari and (part of) the Rangpur districts in the north of the Rajshahi Division of Bangladesh. The total population in this area is 4·2 million (1991 census) and the area size 5655 km^2. In these districts a leprosy control programme has been conducted by the Danish–Bangladesh Leprosy Mission (DBLM) since 1978. MDT was introduced in 1984 and extended to all 4 districts by 1990.

In 1993 numerous small surveys were done within the project area. The objectives of these surveys were both to generate more accurate statistics and as a case-finding activity. The surveys were carried out in small localities which were chosen for various reasons, including a location near clinics and requests from community leaders. The surveys entailed mapping, enumeration, health education programmes, checking and rechecking, using standard forms.

All suspect cases were examined by experienced senior paramedical workers or medical officers for confirmation of the diagnosis. The WHO definition of a case was used, namely 'cases needing treatment'.[5] Skin smears were carried out on cases that subsequently presented to a clinic. Dubious cases were observed for 3 months, examined monthly and subsequently discharged or registered as a true case. During the surveys, leprosy was classified on the spot on clinical grounds according to the Ridley–Jopling scale and by MB/PB classification, where MB include LL and BL cases only, because skin smears were only taken at a later stage.

Definitions used:

New case prevalence rate: New cases detected at the time of the survey per 1000 population.
Active case prevalence rate: New cases and cases already under MDT treatment per 1000 population (= prevalence rate).
Total case prevalence rate: Includes all living cases released from treatment, new, and under treatment per 1000 population.

The *active case prevalence rate* is used in this paper to establish the size of the leprosy problem, in accordance with WHO advice from the Expert Committee.[5]

To obtain a best estimate for Bangladesh as a whole, the abovementioned method was combined with data and information from relevant sources elsewhere in the country, in particular the leprosy NGO programmes. This method has been referred to as the Delphi technique. It has been described as an excellent method of obtaining and refining group judgment based on the premise that a group of experts is better than a single expert when exact knowledge is not available.[6,7]

Results

In 1993, a total of 5096 new patients in Bangladesh started treatment in programmes conducted by leprosy NGOs in various parts of the country (Table 1, Figure 1). This represents nearly 75% of all patients newly detected in Bangladesh during that year, the remaining 25% detected by government health services. Of all new patients, 3307 (65%) were from the Rajshahi Division, mainly from the northern part. Because leprosy NGO control programmes have consistently maintained accurate records and data for many years, their experience and information is important when assessing the leprosy problem in their areas of operation. From that experience it is known that in the southern districts

Table 1. Data from the leprosy NGO programmes in Bangladesh (source: ILEP B forms 1993)

Name project	Division	Population control area	On MDT	New patients 1993	On surveillance or care
DBLM	Rajshahi	4,200,000	2910	1965	6743
RDRS	Rajshahi	2,556,000	1371	458	1790
DLC	Rajshahi	2,288,811	1743	621	2664
DLC	Rajshahi	3,359,716	689	203	527
SLCP	Rajshahi	165,659	60	60	0
SA	Dhaka	133,395	178	74	318
TLCP	Dhaka	7,817,128	311	96	489
MLCP	Dhaka	5,000,000	309	208	759
NLCP	Dhaka	1,671,320	114	34	190
SA	Khulna	33,000	39	33	4
DLC	Khulna	663,340	619	412	763
HEED	Chittagong	1,975,211	760	537	1669
CLCP	Chittagong	7,200,000	1355	395	288
Total		37,063,580	10,458	5096	16,204

Figure 1. Map of Bangladesh. The vertical shaded area is the Rajshahi Division. The horizontal shaded area in the Rajshahi Division indicates the districts where surveys were carried out.

Table 2. Summary of survey results in 4 northern districts of the Rajshahi division of Bangladesh

DMP proportion	Nilphamari	Rangpur	Thakurgaon	Panchagar	Total
Population					
Enumerated	7158	11602	36766	7600	63126
Examined	6766	10373	33450	7283	57882
% examined	94·7%	89·4%	91·0%	95·8%	91·7%
New case prevalence rate	2·7	7·2	2·3	5·9	3·7
M:F ratio	3·2	1·9	1·4	0·7	1·5
Child proportion	0·0%	16·0%	3·9%	37·2%	14·5%
MB proportion	50·0%	26·7%	32·6%	25·6%	30·4%
Active case prevalence rate	4·7	11·1	3·7	7·8	5·7
M:F ratio	4·0	2·1	1·5	0·8	1·7
Child proportion	0·0%	13·9%	4·1%	28·1	11·3
MB proportion	56·4%	42·6%	47·8%	42·15%	45·8%
Total case prevalence rate	8·3	18·5	10·13	12·1	11·7
M:F ratio	2·8	1·8	1·6	0·8	1·6
Child proportion	5·4%	14·8%	4·4%	22·7%	9·8%
MB proportion	55·3%	43·8%	33·7%	36·3%	38·7%

of the Rajshahi Division the problem is less acute than in the northern districts, although occasional surveys have indicated (active case) prevalence rates of 2 per 1000.[8]

Figure 1 shows the districts in which the surveys were conducted. A total of 47 surveys are included in this report; 8 in Panchagar, 27 in Thakurgaon, 3 in Nilphamari and 9 in the Rangpur district. The total population enumerated was 63,126, the number of people actually examined 57,882 (or 91·7%). The average size of the surveys was 1232 (range: 237–3898). Table 2 summarizes the findings of the surveys. The living case prevalence rate for all areas together was 11·7 per 1000. The new case prevalence rate was 3·7 per 1000 and the active-case prevalence rate 5·7 per 1000. The overall male : female ratio is 1·7. The overall proportion of children is 9·8% and the proportion of MB cases 38·7%.

The active-case prevalence rate figure of 5·7 per 1000 undoubtedly reflects the size of the leprosy problem better than the total case prevalence rate (11·7 per 1000), especially in areas where leprosy control activities has been going on for some time and patients have completed treatment. From Table 2 it can be seen that the Rangpur district has both a high living case prevalence rate (18·5 per 1000) and active case prevalence rate (11·1 per 1000). This reflects the particular social situation in that district which has large crowded communities of immigrants from Bihar in India. Also leprosy control activities there have only recently been started.

On the basis of the experience of leprosy control activities of NGOs working in various other parts of the country, together with the results of the surveys reported above, it is possible to estimate the size of the leprosy problem in Bangladesh. This estimation is based on the assumption that the active case prevalence rate is 5 : 1000 in the 8 northern districts of the Rajshahi division, 2 : 1000 in the 8 southern districts of the Rajshahi division and an average of 1 : 1000 in the rest of the country. This is

Table 3. Estimation of active case prevalence rates in the Rajshahi division and other divisions of Bangladesh

Area	Population	Prevalence rate	No. of patients
Northern 8 Rajshahi districts	12,199,000	5:1000	60,995
Southern 8 Rajshahi districts	14,496,000	2:1000	28,992
Other divisions of Bangladesh	83,209,000	1:1000	83,209
Total	109,904,000	1.6:1000	173,196

summarized in Table 3. It is noted that prevalence rates are higher in the districts along the eastern border (the Chittagong Division), compared with the central and coastal districts. According to this calculation, the estimated total number of leprosy patients in Bangladesh is 173,196. This is slightly higher than the official figure of 136,000. Of these, 89,987 (52%) are in the Rajshahi Division. At present, there are approximately 20,000 leprosy patients registered with both government and NGO services in Bangladesh. About 10,000 have completed MDT, and the cumulative MDT coverage percentage for Bangladesh is currently 88·90.[1] If the official WHO figure and our own calculation of the estimated total number of patients are in the right order, it is possible that there are still approximately 150,000 patients who require treatment.

Discussion

It is very difficult to make a reliable estimate of the prevalence of leprosy in a given area or country.[9] Total population examination is both extremely expensive and unnecessary. Sample surveys, the standard method for obtaining information about disease prevalence, need to be large because of the uneven distribution of leprosy. A number of simple methods have been recommended: extrapolation from registered cases, rapid community surveys, extrapolation from child prevalence rates and the Delphi technique (expert opinion). The approach described in this paper combines some of these methods, gaining from the data and local experience of well-established leprosy programmes in various key areas of the country, together with data from surveys conducted in the high endemic districts of the northern Rajshahi Division. The estimated number of leprosy patients using the above methodology (173,196) is only 10% greater than the official estimate. It will be possible in the next few years to see how close this figure is to reality through data from the national leprosy control programme which is now rapidly developing to cover the country.

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