Current status of leprosy and leprosy control in Bangladesh: an ongoing collaboration

S. G. WITHINGTON*, A. N. MAKSUDA**, M. A. HAMID SALIM* & J. U. AHMED**
*The Leprosy And Tuberculosis Coordination Committee, Dhaka, Bangladesh
**Leprosy Elimination Programme, Directorate General of Health Services, Bangladesh

Accepted for publication 24 June 2005

Summary  Elimination of leprosy as a public health problem, defined by a registered prevalence of less than one case per 10,000 population, was achieved by Bangladesh in 1998, and steady reduction in prevalence is ongoing. It is less certain whether a sustained reduction in case detection is occurring, with little overall change in some longstanding programme areas, though the overall annual new case detection rate has fallen by over one-third between 1996 and 2004, from 9.8 to 6.1 per 100,000. Concerns about ‘hidden’ cases have been raised in Bangladesh as elsewhere, though the National Leprosy Elimination Campaign of 1999 detected relatively fewer new cases than in other countries, and mainly in low endemic areas. Investigation into the correct diagnosis of leprosy and recording and reporting practices has not suggested high levels of over-diagnosis or ‘over-registration’. Both before and since achievement of the elimination target at national level, the collaboration of Non-Governmental Organizations with the national Leprosy Elimination Program has been considerable. NGOs now support ongoing leprosy control efforts in rural and urban populations, moderate to high endemic for leprosy, amounting to 50% of the entire population, and NGO staff look after 75% of all new cases in Bangladesh. This close collaboration has highlighted the potential for large-scale partnership in disease control, and has expanded to extensive partnership in tuberculosis control, which will hopefully enhance cost-effectiveness and quality of both programmes. Further challenges remain in the area of urban leprosy control, where leprosy case finding represents 30% of the whole country, but public health infrastructure and community organization is weakest. Sustaining of leprosy services in the long term is a significant concern, and new modes of collaboration, with a more technical, supportive role for NGOs in some areas is being piloted.
Introduction

The World Health Organisation (WHO) target of reducing leprosy prevalence to less than one registered case per 10,000 population as a means of eliminating leprosy as a public health problem, has been reached globally,¹ and also nationally in all but a few high endemic countries. Nevertheless, determining the next steps for leprosy control will require a close analysis of experience over the last 10–20 years on a national and sub-national basis. Despite reaching the elimination target in 1998, Bangladesh continues to be a country with a high burden of leprosy in terms of absolute numbers of new cases, averaging around 8000–10,000 annually. Excellent record keeping and longstanding close collaboration between the National Leprosy Elimination Programme (NLEP) and Non-Government Organizations (NGOs) make Bangladesh an interesting case study in regard to leprosy control.

Nearly 150,000 people have completed multidrug therapy (MDT) in Bangladesh from 1985 until the end of 2004, and MDT has been made available from all 460 rural sub-district health complexes, each of which covers an average population of 250,000, and an area of approximately 300 km² since early 1996. NLEP developed and implemented national guidelines for the diagnosis and treatment of leprosy in 1994, and implemented an extensive training programme for health staff, over the succeeding 3 years. Special programmes have been organized subsequently to enhance community awareness and to involve key opinion makers, as well as to implement specific leprosy elimination campaigns (LECs). This included a national campaign in February 1999, and further localized campaigns, focusing on high endemic pockets.

For over 10 years, leprosy services in Bangladesh have been delivered through a partnership between government health care services and a variety of non-governmental organizations (NGOs) involved in leprosy work, and this collaboration is organized through the National Leprosy and Tuberculosis Coordinating Committee (LTCC). Under a Memorandum of Understanding (MoU) between the Government of Bangladesh and NGO members of the LTCC, first signed in 1994 and renewed periodically, NGOs have been assigned specific areas of control activity to implement the national leprosy programme guidelines. NGOs provide the necessary manpower, training and technical resources, with assistance from government health services at national and local level in terms of clinic facilities, drug procurement, and central coordination, supervision and monitoring. Areas assigned to NGOs under the MoU were those of highest endemicity, and the distribution has remained largely unchanged apart from some gradual geographical extension over the years.

A national workshop on leprosy control in the year of 1993 estimated the undetected burden of leprosy to be around 136,000 cases. A further published estimate 2 years later was 25% higher.² This estimate has, however, been reviewed by WHO and the NLEP as actual case detection was considerably below these projections. During the National Leprosy Elimination Campaign (NLEC) conducted over 6 days in February 1999, overall case finding in the same year was increased by 20%, relative to the previous year.³ In September 1997, an independent evaluation of the NLEP was undertaken⁴ and in December 1998, the national elimination target was reached. A verification process conducted in 2001 confirmed satisfactory and widespread availability of MDT and satisfactory recording and reporting processes.⁵
Data collection

Data on the leprosy control programme are routinely collected and sent to the NLEP headquarters in Dhaka for examination on quarterly and annual basis. Data is segregated by sex, and treatment classification. The definition of a multi-bacillary (MB) case changed from more than nine skin and nerve lesions or slit skin smear positive, to more than five skin lesions (or skin smear positive, if performed) from 1998. From the same year, MB cases have been routinely treated for 12 months, though some NGOs, who still routinely take skin smears, have until recently continued until 24 months in those whose smear shows a high bacteriological index (4 or more). From September 2003, all MDT centres of NGOs received direction from NLEP to follow the 12 months MDT regimen for all MB cases as recommended by the seventh WHO expert committee on leprosy. Incidence of reactions, skin smear positive status (where tested for), and WHO ‘Disability’ Grade II status among new cases are routinely recorded, and evaluated. Population data is derived from extrapolations of the national census data, most recently updated in 2001.

NGOs involved in leprosy control in Bangladesh, and members of the LTCC include three members of the International Federation of Anti-Leprosy Associations (ILEP) members, and five other national and international NGOs. Most are implementing tuberculosis control programmes alongside leprosy work, and work within public health centres in close collaboration with government health colleagues, but employing their own staff, and relying mainly on paramedical workers rather than medical officers. In a few areas, the NGO partner is no longer directly involved in diagnosis and treatment but has moved to a more technical, supportive role. Though national policy affirms passive case detection, some of the NGOs employ very active community awareness programs, as well as implementing home-level follow-up for those with disabilities or those stigmatized and impoverished as a result of leprosy. A few areas, notably urban slums, are still reached by rapid survey approaches. The longest and largest single project collaborating with the NLEP in systematic leprosy control activities is the Danish Bangladesh Leprosy Mission (DBLM), a project of the Leprosy Mission (TLM), from which case detection trends were previously reported in 1996. This project is operating in an area of Bangladesh highly endemic for leprosy, is very active in stimulating community awareness on leprosy for a population exceeding 6 million, and has amassed a wealth of data over a 26-year period. The Damien Foundation has worked in moderate endemic areas for leprosy for over 10 years, carefully documenting leprosy control indicators throughout, and has increased coverage to a population of 29.3 million from 2004. The published Annual Reports of the Damien Foundation, Bangladesh and DBLM were used as the sources of data presented specific to these programmes.

Results

Figure 1 shows trends in new case detection rate and registered prevalence since 1993. At December 31, 2004 the national prevalence rate was 0.5 per 10,000 population and the case detection rate for the same year was 6.1 per 100,000, down from 9.8 in 1996, and the lowest level since widespread expansion of the leprosy elimination programme. Apart from significant falls in 1994 (following reorganization and coverage expansion under the MoU between the national programme and partner NGOs) and 1998 (following reduction in duration of treatment for MB cases), registered prevalence has continued to decline gradually.
over the last 5 years. MB cases represented 35% of new cases in 2004. Visible (WHO Grade 2) Disability rates at diagnosis have fluctuated between 7 and 9% of all new cases over the last 6 years, falling to 6.8% in 2004. Male to female ratio among new case finding has fallen from 1.67 in 1996 to 1.21 in 2004. Among six divisions (sub-national administrative units) of Bangladesh, the highest prevalence at end 2003 was in the north-western Rajshahi Division, i.e. 0.71/10,000, compared with a low of only 0.06/10000 in the southern Barisal Division (Figure 2). A total of eight districts and the two largest urban areas, Dhaka and Chittagong, remained above the elimination level as at the end of 2003. Table 1 shows the data relating to detected leprosy patients over the last 9 years in Bangladesh.

Geographical coverage by NGOs in support of the NLEP has increased to around 50% of the population since 2001. The NGO collaborating areas are endemic and contributing approximately 75% of the country caseload at any point of time. A dramatic fall in the registered prevalence of leprosy per 10,000 population in the DBLM area of coverage (see Figure 3) has not been accompanied by decline in overall new case detection. Interpretation is complicated, however, by expansion of population coverage, and vigorous community awareness programmes in the mid-1990s. In the Damien Foundation areas of coverage,
Table 1. Profile of leprosy cases in Bangladesh 1996–2004

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (million)</td>
<td>115</td>
<td>118</td>
<td>122</td>
<td>125</td>
<td>127</td>
<td>129</td>
<td>131</td>
<td>132</td>
<td>135</td>
</tr>
<tr>
<td>New cases</td>
<td>11226</td>
<td>11320</td>
<td>12361</td>
<td>14232</td>
<td>12137</td>
<td>10742</td>
<td>9844</td>
<td>8712</td>
<td>8242</td>
</tr>
<tr>
<td>Registered cases</td>
<td>13385</td>
<td>13248</td>
<td>10597</td>
<td>10703</td>
<td>8501</td>
<td>8540</td>
<td>8143</td>
<td>6754</td>
<td>6711</td>
</tr>
<tr>
<td>Registered MB cases</td>
<td>7845</td>
<td>8078</td>
<td>5433</td>
<td>6083</td>
<td>5010</td>
<td>4433</td>
<td>4222</td>
<td>3655</td>
<td>3223</td>
</tr>
<tr>
<td>Registered PB cases</td>
<td>5540</td>
<td>5170</td>
<td>5164</td>
<td>4620</td>
<td>3491</td>
<td>4107</td>
<td>4300</td>
<td>3099</td>
<td>3477</td>
</tr>
<tr>
<td>New MB</td>
<td>3814</td>
<td>4000</td>
<td>4253</td>
<td>5358</td>
<td>4035</td>
<td>3590</td>
<td>4300</td>
<td>3099</td>
<td>3477</td>
</tr>
<tr>
<td>New PB</td>
<td>7412</td>
<td>7320</td>
<td>8108</td>
<td>8874</td>
<td>8102</td>
<td>7152</td>
<td>6340</td>
<td>4514</td>
<td>5357</td>
</tr>
<tr>
<td>New grade 2 disability</td>
<td>1266</td>
<td>1328</td>
<td>1111</td>
<td>1238</td>
<td>868</td>
<td>811</td>
<td>712</td>
<td>777</td>
<td>561</td>
</tr>
<tr>
<td>Grade 2%</td>
<td>11.3%</td>
<td>11.7%</td>
<td>9.0%</td>
<td>8.7%</td>
<td>7.2%</td>
<td>7.6%</td>
<td>7.2%</td>
<td>8.9%</td>
<td>6.8%</td>
</tr>
<tr>
<td>Children</td>
<td>1779</td>
<td>1642</td>
<td>2265</td>
<td>2207</td>
<td>1858</td>
<td>1521</td>
<td>1101</td>
<td>783</td>
<td>816</td>
</tr>
<tr>
<td>Male:female ratio</td>
<td>1.67</td>
<td>1.51</td>
<td>1.35</td>
<td>1.34</td>
<td>1.42</td>
<td>1.43</td>
<td>N/A</td>
<td>1.22</td>
<td>1.21</td>
</tr>
<tr>
<td>Prevalence rate**</td>
<td>1.16</td>
<td>1.12</td>
<td>0.87</td>
<td>0.86</td>
<td>0.67</td>
<td>0.66</td>
<td>0.62</td>
<td>0.51</td>
<td>0.50</td>
</tr>
</tbody>
</table>

* New case detection rate calculated per 100,000 population.

** Prevalence rate includes those registered for treatment on 31st December per 10,000 population.
similarly, despite consistent application of MDT treatment and a prevalence below the elimination target sustained throughout this period, there is as yet no definite downward trend in detection of overall cases and important sub-groups (see Figures 4 and 6).

Discussion

The striking feature of leprosy control in Bangladesh is the extensive and ongoing partnership entered into between government and non-government organizations during the entire period of MDT implementation and expansion. This partnership now covers half of the entire population and looks after at least three-quarters of the new leprosy cases. NGO projects tend to work in a narrow spectrum of disease, either leprosy alone or with tuberculosis treatment, but deliver these services within government health care facilities, in close collaboration with local health authorities, and according to the national guidelines. NGO implemented areas have usually specifically targeted areas believed to have a high prevalence of leprosy and have also focused on prevention, rehabilitation, referral services and long term care of people

Figure 3. Leprosy new case detection and prevalence rates under Danish Bangladesh Leprosy Mission (DBLM) over 27 years (n = 42,023 registered patients from 1977 to 2004).

Figure 4. Prevalence and new case detection rates under Damien Foundation Bangladesh (population coverage 29.3 million population at end 2004).
disabled and stigmatized by leprosy. They are also active in community awareness and sometimes employ survey methodologies, which have yielded a much higher paucibacillary (PB) leprosy percentage among new cases, and have brought down disability rates correspondingly. Nevertheless disability rates among new cases are highest among NGO-implemented areas in Bangladesh, raising concerns about detection and recording of disability at diagnosis and beyond in areas covered only by routine primary health care services.

Comparison with other countries is not straightforward. In Declercq and Guedenon’s editorial on the African situation, they note the overall positive signs in the declining prevalence and ‘normalization’ of leprosy as part of the integration process. Nevertheless, the picture is mixed. For some African countries at least, especially where conflict is widespread, overall data reliability may be questionable. Disability rates in Africa also remain high relative to global levels and to India in particular, at 11.7% on average. This is somewhat higher than Bangladesh as a whole, though similar to many NGO-implemented areas. Concerns have been raised about leprosy cases remaining hidden worldwide through complacency of health services post-elimination, though efforts to explore the issue are

Figure 5. MB, smear positive, and grade II disability rates per 10,000 population among new cases in DBLM over 27 years.

Figure 6. MB and grade II disability rates under Damien Foundation Bangladesh 1991–2004.
often costly, and, as Krishnamurthy points out, underdiagnosis may be less attractive an issue for program managers to explore than overdiagnosis. Specific attempts to estimate hidden case prevalence through formulae, as proposed by Ferreira et al. from Brazil, are vulnerable to inadequacy of underlying data collection. They may also assume a rather static view of the situation, proposing a constant of between 2 and 5 times prevalence of hidden cases in excess of registered cases in established leprosy control programmes, and more where programmes are not implemented. Justifying these constants, estimating beyond any control programme data, and extrapolating to other settings in different phases of leprosy control work seems problematic, though they may be helpful in practice in some situations. As several authors have indicated, at least until the year 2000, there has been no evidence of a decrease in global incidence of leprosy, and the six most high endemic countries (India, Brazil, Myanmar, Madagascar, Nepal, Mozambique) showed an increase in case detection between 1995 and 2000. Though this is presumably related to intense case detection activities and raised leprosy profile through leprosy elimination activities, more recently observed falls in global leprosy case detection, as also in Bangladesh, may well be simply related to the withdrawal of the same. Effects on underlying incidence remain uncertain.

Globally, LECs have been widely used to locate ‘hidden’ cases of leprosy, and mobilize resources for leprosy control. Such campaign activities, at least on a large scale, have been relatively few in Bangladesh compared with its neighbours. The National LEC conducted in February 1999 resulted in 2435 new cases over a period of 1 month following an intensive week-long campaign. This compares with a total of 12361 cases in the entire year before the campaign, and was far lower than increases recorded in LECs conducted in the nearby Indian states of Bihar and Orissa. One concern expressed over LECs is that effects may be short-lived and, as Croft has pointed out, they tend to be best implemented where leprosy control is most well organized, and least needed. It is interesting to note that, in the Bangladesh NLEC, very little relative increase in new cases over routine case detection was noted in NGO-implemented areas. By contrast, there was a significant increase in case finding in low endemic areas. Nevertheless resources for campaigns are still largely concentrated on high-endemic, better-resourced NGO-partnership areas, although attention has shifted more recently to possible over-diagnosis. In the last 12 months several special programmes including ‘mop-up exercises’ which stress cluster survey, register review, and case verification as well as ‘situation analyses’ have been conducted by the national programme in these locations. These have confirmed that diagnosis in these areas is largely accurate, register maintenance is relatively good, and there remain significant numbers of new cases.

There has been considerable variation in the profile and prevalence of leprosy throughout Bangladesh. While the actual case finding rates have not reached levels consistent with the initial estimates of leprosy prevalence in Bangladesh, substantial numbers of people with leprosy are still being newly diagnosed, and the WHO grade 2 disability rate is still over 5%. In some areas, perhaps more isolated historically from the rest of the sub-continent because of a vast network of small rivers and canals, especially the sprawling southern river delta in the Barisal and Khulna Divisions, the prevalence rates have always been low (see Figure 2), and there is minimal NGO collaboration, especially in the former. By contrast, in the northwestern Rajshahi Division of the country, bounded in south and east by the Padma (Ganges) and Jamuna (Brahmaputra) rivers, where NGOs are collaborating in the entire division, leprosy prevalence remains above the elimination target in several districts, and in the whole division until 2002. The south east of the country, adjacent to Myanmar has also had relatively higher leprosy case detection rates, though the inaccessibility of the three hilly
districts, for security and geographical reasons, has complicated a full assessment of the situation. Since the commencement of a new initiative in these districts, through collaboration between The Leprosy Mission and the local Government health services in mid 2002, the prevalence has risen from below one to over 2.5/10,000 population in each of the three districts, with around 70% of cases being MB, and WHO grade 2 disability rates of over 20%.

While clearly more expensive, the focused NGO approach to and direct responsibility for leprosy control in Bangladesh has facilitated field based research of quality and on a large scale. Important examples include the BANDS19 and TRIPOD research projects. The former is a descriptive study reviewing nerve function impairment in a large cohort of new cases that resulted in the development of a clinical rule to predict risk of nerve function impairment in new leprosy cases.20 TRIPOD investigated the potential role of corticosteroid prophylaxis for nerve damage in new MB patients,21 and explored aspects of early detection22 as well as late treatment of nerve damage due to leprosy.23 A further trial into household transmission, and prophylaxis of contacts by rifampicin, known as COLEP24 is underway. The latter study and previous formal but less well-controlled surveys in the DBLM area (data unpublished) show leprosy prevalence rates among those surveyed around five-fold higher than routinely detected, even by the active programme operating in the area, and suggest a very significant remaining case-load of leprosy. Even considering the probable detection by such active ‘screening’ methodologies of many leprosy lesions that would self-heal, the results suggest a ‘tip-of-the-iceberg’ phenomenon in routinely reported leprosy case data. Such studies lend caution to the general note of optimism regarding the effectiveness of sustained and widespread availability MDT to impact the transmission of leprosy.

Reorganization of health services has clearly had a significant impact on leprosy services in India, following integration into primary health care and long term results are awaited eagerly. The Latin American experience of decentralizing health care in relation to leprosy control services has been reported to be mixed, relatively well controlled and positive in Brazil but coming close to inducing collapse in Colombia.25 Bangladesh, by contrast, has maintained a mix of integration of leprosy into public health units with ongoing specialist partnership input from NGOs, and plans for further decentralization of the health system have been put on hold. A major challenge remains in Bangladesh as to how to sustain MDT services and leprosy control into the future. It is of note that in the two areas presented of longstanding Government-NGO collaboration, the total new case finding has remained relatively static over long periods of time whether at a level above the elimination target or below the target. In the case of DBLM, the higher endemic area, there has been a clear and dramatic fall in population-based rates of new MB, visibly deformed, and smear positive cases (Figure 5), but this is not the case in the lower endemic areas of Damien Foundation (Figure 6). The close involvement of NGOs has been a strength of the national programme but raises questions of sustainability, especially as attracting funds may be difficult in a post-elimination context where the cost per case of detection and treatment is inevitably increased. Integrating TB into existing leprosy programmes has been reported and recommended by some,26,27 and has been widely used by NGOs in Bangladesh, with reported benefits for both programmes.28 Much of the progress in strengthening and expansion of the tuberculosis control programme in Bangladesh has built on pre-existing partnership between Government and NGOs in leprosy control, and is likely to improve cost-effectiveness in work of NGOs, especially as leprosy prevalence declines.
Leprosy treatment is available from all rural health complexes in Bangladesh at the sub-district level alongside general health treatment, whether or not NGOs are participating in a given area. Despite this accessibility, some government centers suffer particularly from a lack of motivated and well-trained health workers. This is reflected in concerns over unsatisfactory health service quality, and may contribute to low case finding of leprosy in areas covered by government alone. Further integration of NGO-implemented leprosy control services into the routine health service delivery package of the government is underway in some areas where the elimination target has been reached and the local primary health care service is ready, willing and trained to take over this responsibility. The need for capacity building, regular uninterrupted supply of drugs and consumables, and regular support from trained supervisors, together with present problems in regularization of employment and salaries of some Government health staff suggest a cautious and well-planned approach. Given the extensive collaboration thus far, the outcome of this integration process is important, including whether a new role of providing technical assistance by the NGO sector rather than direct service provision will succeed as hoped. The problem of fully integrating with existing primary health care service delivery is most acute in the major cities of Dhaka and Chittagong. These metropolitan areas were responsible for over 30% of all new leprosy cases in Bangladesh in 2003, and present significant problems of MDT completion for mobile slum-dwellers. While a plethora of private practitioners, specialist services, and hospitals are available in the cities, the primary health care infrastructure remains weaker than in rural settings. Community organization is also generally much weaker in the cities, especially in slums, but community-based options may need to be explored and strengthened in order to pilot innovative modes of sustaining community awareness, self-care for disabilities, and leprosy control service delivery.

Acknowledgements

The authors would like to acknowledge the National Leprosy Elimination Program and the NGO partners of the Leprosy and Tuberculosis Coordinating Committee, especially the Damien Foundation and the Leprosy Mission, and their staff for their essential support and provision of necessary data.

References

11 Krishnamurthy P. Hidden leprosy – who is hiding from whom?. *Lepr Rev*, 2004; **75**: 303–305.
17 Jianping S *et al.* Analysis on the detection of leprosy cases before, during and after the year of leprosy elimination campaigns. *Lepr Rev*, 2004; **75**: 157–163.
24 Moet FJ *et al.* A study on transmission and a trial of chemoprophylaxis in contacts of leprosy patients: design, methodology and recruitment findings of COLEP. *Lepr Rev*, 2004; **75**: 376–388.
28 Croft RA, Croft RP. Tuberculosis control is good for established leprosy programmes. *Lepr Rev*, 1997; **68**: 139–146.