Early diagnosis of leprosy and the care of persons affected by the disease in a low endemic area
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Chapter 8

General discussion
This study has confirmed that leprosy has been eliminated as a public health problem in Shandong. It suggests that public health approaches to the discovery of cases of leprosy are no longer cost-effective, but the finding and treatment of cases needs to be integrated into the general health services. Passive case finding in the post-elimination phase requires certain skills and knowledge amongst general health workers and dermatologists. This study suggests that those skills, particularly with respect to the knowledge and examination of peripheral nerves, needs to be improved and maintained. Services that help prevent disability related to leprosy have been shown to be effective in Shandong Province; impairment of nerve function can be reversed by early detection and treatment with corticosteroids, and secondary impairments can be reduced or even prevented through patient-based self-care approaches. For these reasons, it is recommended that such services be expanded to other provinces. Finally, social and economic rehabilitation is needed for those disabled by leprosy; leprosaria need to be restructured, since only a small number of former patients remain in these leprosy colonies (12 people on average), and maintenance of these villages in Shandong is not cost-effective.

Integration of leprosy services into general health services

Since the elimination of leprosy in Shandong (1994) and in China (1998), maintenance of a vertical leprosy control programme is no longer effective. One option to deal with the remaining problems is to integrate the leprosy control programme into general health services. The integration of leprosy services into the general health services has been well documented and discussed, and this strategy has been adopted in many countries. The rationale for the integration is the development of a cost-effective and sustainable way to manage remaining leprosy problems in a low endemic situation. This includes early detection and treatment of the few incident cases, as well as comprehensive care for the prevention of disabilities and the rehabilitation of patients through effective coverage of the population by accessible and efficient health services, which are acceptable to both the community and the patients.

On the basis of an epidemiological analysis, in 1995 we proposed the integration of the leprosy control programme into general health services in Shandong, in order to sustain efforts to manage the remaining problems and to increase the cost-effectiveness in a low endemic situation. However, before such integration is undertaken, there must be situation analysis and careful planning. The experience of integration in Tamil Nadu, India, demonstrated that the quality of leprosy control activities was jeopardized without careful preparation beforehand. Since 2003, the Netherlands Leprosy Relief (NLR) has supported this process in five provinces of China. However, the leprosy control programmes in China including Shandong have not been successful for the full integration, because the health system reforms in China, which started in the late 1990s after the collapse of the well-established infrastructure of the health system in general and the rural cooperative health care
system in particular, are still underway. Without full restoration of systems, it is
difficult to start integration, because a sound health care infrastructure is one of the
prerequisites for the integration of a leprosy control programme into the general
health services.4

As leprosy is eliminated in most provinces in China, support for the vertical control
programme will be further reduced. Yet, the control programme must be sustained to
manage remaining problems, so integration of the programme into general health
services should again be considered. An in-depth discussion of this issue is beyond
the scope of this thesis, but in general, one can say that leprosy control in a low
endemic situation must focus on three components: early detection of the few incident
cases to reduce the risk of development of impairment/disability; provision of a high
quality of case management including treatment with MDT; and continuing support
for those who are already disabled and those who are disadvantaged.12 Although the
prerequisites for full integration may not yet be met, the integration of case detection
and management may be started and then gradually expanded to include other
activities, such as disability prevention and rehabilitation.

**Limited role of public health approaches to early diagnosis of leprosy in the
post-elimination era**

Early diagnosis is key in a leprosy control programme.13 Delay in diagnosis will allow
the existence of the infectious source, continued transmission of the disease in a
community, and increased risk of development of nerve function impairment and
disability in the affected individuals, which often leads to a series of complications
and consequences.14 Delay in diagnosis is such an important issue for both individuals
and the community that many studies have addressed it.14-18 However, in a low
endemic area for leprosy, such as in Shandong and China as a whole, the issue of
effectiveness and feasibility of early diagnosis of the few incident new cases scattered
amongst a large population remains to be addressed.

In areas where leprosy is endemic, various methods are used for case detection, such
as population surveys, rapid surveys, contact surveys, self-reporting through health
promotion campaigns, and referrals by health care providers. Rapid village surveys
(RVS), known as "clue" surveys in China, are mainly used as a case-finding tool.19 In
our study no cases were found by the RVS conducted in a county where the disease
was formerly endemic. This was confirmed by experiences in other provinces in
China in which leprosy has been eliminated, in contrast to the areas where leprosy is
highly endemic. In highly endemic areas the RVS is used both to estimate the size of
the leprosy problem and to identify additional cases.20 For example, an RVS
conducted in two districts of East Java, Indonesia, demonstrated that the prevalence
rate of leprosy was more than twice that expected on the basis of cases in treatment.21
In a north-eastern province of Thailand the number of new cases found with an RVS,
which was similar in method to the "clue" survey in China, matched the number in the
total village survey. However, in China, where there is a low endemicity for leprosy and a few new incident patients are scattered throughout a large population, an RVS ("clue" survey) does not appear to be an appropriate tool in case detection.

Contact tracing, another common and important method in case finding, has also been used in leprosy control programmes, including those in China. In high endemic areas, distance and genetic relationship are the major determinants for the development of clinical leprosy in those who have contact with leprosy patients. However, this method has lost its value in identifying new cases in the low endemic area of Shandong. Our analysis demonstrated that only 2.2% of all leprosy cases were identified by contact examination in 5 years of follow-up. This can be explained by the long incubation period (21 years on average in our data). To my knowledge, there are no other reports on the effectiveness of contact tracing for leprosy in a low endemic area, although the cluster of leprosy patients in household contacts tends to be more significant in a low endemic area than in a high endemic area.

Health-seeking behaviour is a very complicated issue. Every community exhibits a unique mix of cultural attitudes and knowledge that associate simple symptoms of disease with recognized help-seeking actions. There has been no formal report on the health-seeking behaviour related to leprosy in China. Identifying what people with leprosy think and why and how they behave will help the programme managers design an appropriate intervention strategy.

A health promotion campaign or health education programme on leprosy for the general public aimed at encouraging people to self-report when they suspect they may have leprosy has been advocated by WHO in a low endemic situation. However, such an education programme should overcome the fear and stigmatization of leprosy, which are so deeply rooted owing to the infectiousness of the disease and the disability it causes. Therefore, many patients may deny having the disease to avoid discrimination, resulting in delay in diagnosis and treatment. Reports on the effectiveness and efficacy of public health education in identifying new cases of leprosy in a low endemic situation are lacking, and there probably never will be such a study, because the prevalence and incidence of leprosy are too low to assess the effectiveness of such a campaign.

Leprosy mainly affects skin and peripheral nerves. Many patients with early disease may visit general health services or dermatologists without suspecting that they have leprosy. Therefore, the diagnostic knowledge and skills of health care providers at different levels will play an important role in finding these new cases. This suggests that health staff at basic levels such as rural doctors and health care providers at township level need a brief, but practical training programme in managing the most common and simple problems and in recognizing cases that are suggestive of leprosy, such as in a patient with a pale or erythematic, patchy rash, without the construction of a long differential diagnosis. In Mali, a short training programme on
basic dermatological skills for the detection of leprosy at the primary health care level clearly demonstrated a significant improvement in the skill of trainees in managing patients suspected of having leprosy. After the training, many patients, including some who actually had the disease, were referred to a specialized service for confirmation of the diagnosis.32 Training such as this should be offered periodically to meet the needs of staff turnover and can be organized in combination with periodic local health meetings to increase the cost-effectiveness. The presentation of the training via CD ROM is recommended, because the material can be prepared at the provincial or national level to maintain the standard of quality.

During the past 11 years, 80% of new leprosy cases in Shandong have been diagnosed through dermatological services. However, as leprosy has become a rare skin disease, dermatologists, especially those recently trained, have had less chance to gain experience with new patients. This can explain in part why occasionally some patients have visited dermatological services several times before the diagnosis has been made; it is because ‘the first step towards diagnosing leprosy is to think of the possibility of leprosy’.33 The importance of such training cannot be underestimated, because up to one third of cases of leprosy do not satisfy the diagnostic criteria based only on the cardinal signs.34 Among the dermatologists assessed in our study, there was a lack of skills in palpating commonly involved peripheral nerves and assessing nerve function. This lack needs to be addressed in a future training programme, despite the additional finding in our study that the reliability of judgment of peripheral nerve enlargement is questionable. Further studies are needed to clarify the issue of reliability.

In recent years, at annual meetings of the Shandong Provincial Dermatological Association, efforts have been made to train dermatologists with the use of pictures of patients diagnosed with leprosy during the past year. This training has been organized by the provincial institute of dermatology with financial support from the provincial bureau of health. Training for dermatologists and rural doctors in the province will continue in cooperation with other continuing education programmes in the province. It is hoped that these efforts in the long term will benefit the province by the early diagnosis of leprosy, although the effect is difficult to assess because of the small number of new cases identified each year. Open channels of communication between the leprosy control programme and the referring dermatologists are also necessary. Feedback on the referral (whether a patient is diagnosed with leprosy or not) should be provided. Incorporation of leprosy into the curricula of medical faculties should continue, with opportunities to see and examine patients whenever possible.5

Prevention of disability (POD) and rehabilitation

At the end of 2006, out of 53,484 leprosy cases registered in the province, more than 15,000 former patients were alive, and 50% of those were living with WHO grade-2 disability. These persons are the potential clients for the main task of prevention of disability (POD) and for social and economic rehabilitation (SER) programmes.
Rehabilitation should be considered not only for the person affected by leprosy, but also for that person’s family as a unit. Our pilot project on POD showed that the most impressive achievement was the remarkable reduction in number of secondary impairments. Newly diagnosed patients should be educated about POD. In particular, those who already have nerve impairment at diagnosis should receive POD education in combination with MDT therapy, apart from treatment with corticosteroids based on the assessment of nerve function and duration of nerve impairment.

Since nerve impairments are irreversible in most patients with leprosy, especially in those who have had the nerve impairment for a long time, and their condition often deteriorates further even after the disease is cured, POD will be a life-long matter. Efforts should be made to sustain such disability prevention, i.e., patients need to learn self-care and continue to practice what they have learned. Frequently, POD itself is not enough to meet the needs of people affected by leprosy. A strategy to manage social and economic problems must be developed and implemented. In this post-elimination era in Shandong province and in many other provinces in China, SER of people affected by leprosy is now a major priority and a vital aspect of control programmes. The principles and approaches of SER have been addressed fully in the ‘Guidelines for Social and Economic Rehabilitation’. So far, there is no such SER programme either in China or Shandong. The data on people affected by leprosy in Shandong provide some basic information for preparing an SER project in the future, but more details are needed, because understanding the needs is the first step in designing a SER programme. For example, answers are required to questions like who needs what kind of help, such as money or housing, and in what ways can people be helped. With the support of the central government, a follow-up project to collect detailed data on all people affected by leprosy is being prepared. All the patients will be regrouped according to their situation and their needs. Then, strategies can be developed to provide better care for them.

There are 50 leprosy villages/leprosaria in Shandong, where 546 people live. The vast majority is former leprosy patients, and only a few are taking MDT. The average age is 64.6 years, and the WHO grade-2 disability rate is as high as 90%. The living standard is low, and some social stigma remains against the residents. Since most leprosy villages have few people and are located in remote areas, managing them is difficult and not cost-effective. Last year the central government initiated a project to reconstruct leprosy villages throughout China to provide better care for these abandoned and dependent people. According to the plan, only a few leprosy village/leprosaria will remain, and most of the small ones will be closed in order to increase cost-effectiveness. Data obtained from our study presented in chapter 7 of this thesis and the suggestions in a previous survey on leprosy villages in the province, together with one other report, have provided useful information for the policy-making and planning in this process.
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