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

Chapter 1, the general introduction, describes leprosy as one of the oldest diseases in human beings, with a unique social dimension. Nerve impairments and related social stigma can lead to many social and economic problems, such as unemployment, poverty, community dislocation and destitution, for patients and also their families. Since multi-drug therapy (MDT) was introduced for the treatment of leprosy in 1981, millions of patients have been cured and released from leprosy control programmes, and the prevalence of leprosy has dramatically declined worldwide. Epidemiologically, leprosy in China, including in Shandong province, shows a similar trend. The goal of elimination of leprosy was achieved in Shandong in 1994.

However, the magnitude of suffering cannot be adequately expressed in quantitative terms, and the number of patients in need of chemotherapy for leprosy does not sufficiently reflect the problem. Even after elimination of the disease, there still is a need to maintain epidemiological surveillance because the distribution of leprosy is uneven, and different strategies will have to be developed to deal with the small number of incident cases. Furthermore, more than half of the patients who have been cured of leprosy still suffer from disabilities and are in need of rehabilitation, which has become the priority in a leprosy control programme. The strategy to eliminate leprosy will have failed if disability is not prevented. This thesis describes strategies to manage the three components of leprosy control programme in a low endemic situation such as in Shandong province, China: case detection, early diagnosis, and prevention of disability with rehabilitation.

Case detection
The prevalence and detection rates of leprosy in Shandong started to fall in the early 1980s, and a further decline was facilitated by the introduction of MDT in the late 1980s. On average, approximately 50 new cases have been detected annually in the last 10 years (range: 30-75). The delay in making the diagnosis, however, has remained considerable. We suspected that more patients than reported were hidden in the community. Yet, as described in chapter 2 of this thesis, no persons with leprosy were found in a rapid village survey covering 10% of the population in a county of the province where leprosy was formerly endemic. Although the quality of the survey can be questioned because of the use of dermatological services during a short period in each village, we think that it is likely that there are few, if any, leprosy cases left in Shandong.

Early diagnosis
The studies in chapters 3.1 and 3.2 describe the level of knowledge and skills in the early diagnosis of leprosy among general health staff and dermatologists. Utilization of general health workers at different levels is one of the options in finding early cases of leprosy in a low endemic situation. The first cross-sectional study demonstrated
that the ability among the staff in general health service to recognize early symptoms and signs of leprosy was low. A possible explanation is that the previous training programme for rural doctors and paramedical doctors involved in a leprosy control programme at the township level did not include task assignment or orientation regarding the early diagnosis of leprosy. More efforts for training are needed. Dermatologists had a higher level of knowledge than rural and paramedical doctors, but the sample of dermatologists in the study was small and only on a provincial level.

To understand the general level of knowledge and skills in the early diagnosis of leprosy among the doctors in dermatological services at different levels throughout the province, a second survey was conducted. Out of the 158 doctors assessed, 63% had a poor ability to recognize the early signs of leprosy. A better knowledge was correlated with every experience a doctor had in treating a patient with leprosy. This can partly explain why some patients had to visit dermatological services many times before the diagnosis of leprosy was made. Other important findings in the study were that a stigma towards leprosy still existed to some extent among the doctors and there was a lack of referral channels between the doctors in dermatological services of general hospitals and those in the leprosy control programme. The importance of training and training methods was discussed. The establishment of an effective channel between the dermatologists and the leprosy control programme is also needed.

Chapter 4 addresses the value of the examination of household contacts in case finding. Since the development of overt clinical leprosy depends on exposure and on the susceptibility of an individual to an infection with *M. leprae*, household contacts are generally considered at higher risk for the occurrence of the disease. Therefore, such an examination has been used as an important strategy in case finding in many leprosy control programmes.

The proportion of the total number of leprosy cases detected among household contacts generally tends to be approximately 20 to 30%. These figures for China and Shandong are about 20% and 16%, respectively. However, on average the incubation time between the index case and the secondary case in the families among the 90 index cases in our study was 21 years. If we had followed the index cases for 5 years, only 12 cases (2.2%) would have been detected. This means that the contribution of household contact examination in terms of the early diagnosis and treatment of leprosy in a low endemic situation is small. Practically, frequent household contact examination often causes stigma and discrimination against the patient and even the whole family, because it impresses on the public that the disease is very infectious and incurable. Obviously, other strategies have to be developed for early case detection.

Chapter 5 describes another important issue in diagnosis of leprosy, i.e., the inter-reliability in assessment of sensation of skin lesions and nerve enlargement. The clinical diagnosis of leprosy is based on the three cardinal signs: anaesthesia of skin
lesions, enlargement of peripheral nerves, and a positive skin smear. However, there is no standardized method for the examination of anaesthetic skin lesions and for palpation of peripheral nerves. This is particularly important in the diagnosis of paucibacillary leprosy, because the skin smear examination is often negative in these cases. The results in this study showed that the inter-reliability of both sensory testing and palpation of nerves was unsatisfactory between different pairs of testers, suggesting that practical training for the diagnosis of leprosy should be strengthened as much as possible. Ongoing training and regular supervision are necessary to improve the skills of the staff. Development of a new, simple, and reliable test that can be used in the field or in clinical settings is needed.

**Prevention of disability and rehabilitation**

In *chapter 6*, the results and experiences of the prevention of disability (POD) are described. This pilot project was conducted in collaboration with the Ministry of Health, China, and The Leprosy Mission International, and included 1132 cases selected from 6 counties. After a 3-year implementation, the most impressive achievement was the remarkable reduction in number of secondary impairments, with a reduction of 97% in red eye, 94% in open cracks and wounds of hands, and 75% in foot wounds. This led to a marked increase of confidence in the POD project in both patients and staff. Strong government commitment, strengthened training of staff at different levels, and periodic supervision are the main factors for success. Sustainability of the project is the key for benefiting patients in the long term. It is clearly essential that patients have the motivation, knowledge, and ability to continue self-care and other activities for an often indefinite duration. An overall plan, perhaps combining self-care with community-based rehabilitation, is needed, so that the full potential of the approach becomes truly sustainable.

In *chapter 7*, the social, economic, and medical needs of former patients living in leprosy villages in the province are described. To provide better care for the former patients and to better use existing resources cost-effectively, it is proposed to combine small leprosy villages into a few larger, already existing leprosy villages with better facilities. This restructuring of leprosy villages would impact not only the former patients’ lives (most of them have had to move far from their hometowns) but also those of the local leprosy control staff, and even the leprosy control programme, because the staff of small leprosy villages would have to look for new jobs and local governments could cut off financial support for leprosy services. In this survey it was showed that the basic needs for living have been guaranteed by local governments, but at a low level. Medical care has not been satisfactory, as many health problems related and unrelated to leprosy have increased. The self-care issue needs to be addressed, as the dependents grow older and the disability status worsens. The majority of the former patients, medical staff, and government officials who were interviewed agreed with a restructuring of leprosy villages. Most government officials and medical staff pointed out that government commitment at the top level was needed. The information gathered in this qualitative study can be used for policy
making and for planning the of leprosy villages in Shandong in future.

Chapter 8 offers a general discussion of the studies in this thesis. Epidemiologically, leprosy in no longer a major public health problem in Shandong and in many parts of China. However, the number of patients with leprosy does not sufficiently reflect the magnitude of the problem. A leprosy control programme is needed to deal with the early diagnosis and treatment of the few incident new cases and to monitor nerve impairment among those cases. Prevention of disability (POD) and rehabilitation has become a priority in the care of those whose disability has already developed. There is also a need to care for those who have been dislocated from their communities and are destitute. Since public approaches in case finding are no longer cost-effective in a low endemic situation such as in Shandong, training of medical staff, including dermatologists at different levels, to improve their knowledge and skills in diagnosis and to remind them of the possibility of leprosy in their daily services will play an important role in the early diagnosis of the disease. Utilization of the existing leprosy services in POD has demonstrated that the secondary impairments can be prevented, but government commitment is essential for the sustainability of these services. Social and economic rehabilitation, including the care of those who have already experienced dislocation and destitution, is a more complicated issue. It needs to be addressed not only by careful planning and strengthened training but also by strong government commitment at the highest level with financial support.