Early diagnosis of leprosy and the care of persons affected by the disease in a low endemic area
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CHAPTER 7

Qualitative assessment of social, economic and medical needs for the ex-leprosy patients living in leprosy villages in Shandong province, the People’s Republic of China

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SUMMARY

After successful control of the endemic of leprosy in Shandong Province, China, how to deal with the ex-leprosy patients living in the leprosy villages/leprosaria has become a hot point among programme managers, medical staff and governmental officials at different levels. One of the possible solutions in dealing with the problem was proposed to combine small leprosy villages into a few larger, already existing, leprosaria/leprosy villages with better facilities, in order to provide better care for ex-leprosy patients and make better use of the existing resources. With this assumption, social, economic and medical needs felt by the ex-leprosy patients in three leprosy villages of Shandong province were assessed qualitatively, and the possibilities and the obstacles regarding combination were explored. The results showed that the basic needs for living, such as food and clothes, were provided by state governments, although living standards remained at a low level. Medical care was not satisfactory, as many health problems related and unrelated to leprosy were increasing, and self-care needed to be addressed, as the dependents grew older and the disability status became worse. Although the majority of ex-leprosy patients, medical staff and government officials interviewed agreed with the idea of the adjustment of leprosy villages/leprosaria, some obstacles, including stigma, existed. Government commitment, ideally at top level, was needed in order to facilitate the process of combination.
INTRODUCTION

Much effort has been transferred to the prevention of disability (POD) in the past decades, including China and Shandong Province, after the successful control of endemic leprosy. However, the problems caused by leprosy are not merely health-related in nature. The impairments and related social stigma (sometimes stigma alone without impairment) can lead to many social and economic problems for patients, and sometimes even also their families, such as unemployment, poverty, community dislocation and destitution, which is neglected in most leprosy control programmes.

In the past and even until recently, leprosy villages/leprosaria were established to isolate the patients, either to stop the transmission of the infection and/or to provide care for leprosy sufferers, in many parts of the world, including China. With the reduction in prevalence of leprosy, the number of patients needing treatment in leprosy villages and hospitals decreased. At the same time, with the health structure reforms of recent decades in many developing countries, vertical leprosy control programmes have been integrated into general health services in order to use the existing resources effectively and to reduce the stigma caused by the isolation of the leprosy patients. However, little information is available on how the leprosy villages and the people affected by leprosy have been dealt with after the leprosy control programme has been integrated into the general health services. Although recently the quality of medical care for the leprosy patients on treatment has been explored qualitatively in Nepal, information on the socio-economic and medical care needs felt by the ex-leprosy patients living in leprosy villages is limited.

In our previous survey, we described in general the history and the present situation of the leprosy villages/leprosaria in Shandong province. Briefly, most people affected by leprosy living in those resettlements were old, the living standard was low, a vast majority of the ex-patients (89%) had WHO grade-2 disability and many of them had become dependents. On the other hand, many houses that were built before 1970s have now been destroyed and the land had become fallow or had to be rented to farmers outside the villages at a lower price due to lack of labourers in the leprosy villages. Waste of resources is the result. Furthermore, due to the stigma and isolated location of the leprosy villages, communication of the ex-leprosy patients living in the leprosy villages with the general population is also limited.

How to take care of these elderly and the disabled people affected by leprosy has become an important question in leprosy control programme in Shandong, and in China as a whole. The aim of our survey was to assess the social, economic and medical needs of the ex-leprosy patients living in leprosy villages/leprosaria in Shandong province, in order to design a proper social and economic rehabilitation project and/or to provide better care for the ex-leprosy patients living in leprosy villages.
villages in a cost-effectiveness way, with an assumption that the leprosy villages would be combined. Possibilities and obstacles in the adjustment of leprosy villages in Shandong were explored by triangulation.

**MATERIALS AND METHODS**

*Selection of study settings and study population*

This is a descriptive exploratory study. A purposeful sampling method was used. Three leprosy villages were selected among 51 leprosy villages (leprosaria) in Shandong according to the number of ex-leprosy patients. One represented better conditions in a leprosaria/large leprosy village (with more than 30 people), in Shandong, one represented poor conditions in a leprosy village (with fewer than 10 people) and one was in between.

The subjects selected included: (1) key people in the leprosy villages including members of leprosy village committee; (2) medical staff responsible for the leprosy control programme and (3) officials from the health authority and government departments such as the financial department, association of disabled and civil departments.

There were 54 people affected by leprosy living in Anqiu leprosy village. The age, disability status and sex were taken into consideration in the selection of the interviewees. Since most people were disabled and majority was males, all non-disabled people and females were included in the interview. In Feixian and Dongyin leprosy villages, all the people were included in the interview, as the number of the people affected by leprosy in the two villages was small.

*Data collection tools*

In addressing the social, economic and medical needs of the people affected by leprosy living in leprosy villages and resources, a descriptive framework of the needs and resources was established. In the framework, three categories of needs were identified: social, economic and medical. The aim of social and economic rehabilitation is to restore to normal the esteem and dignity of those affected by leprosy, and to provide better care for those who are too old and/or too disabled to take care of themselves.

The data collection tools included the following:

1. Focus group discussion (FGD) in exploring the social and economic condition and the needs felt by the ex-patients in the villages (the topics for FGD are presented in the Appendix). Since the government’s plan is to combine the small villages, the ex-patients have to move from the villages near their home towns to other places in the province, and therefore opinions from all stakeholders involved need be
explored and discussed. We conducted one FGD for people affected by leprosy in Anqiu leprosy village, two with medical staff and two with government officials in Anqiu and Ferxian counties.

2. An interview with a loosely structured questionnaire for the people affected by leprosy living in the three selected leprosy villages.

3. The observational method was used to cross check with the data collected from interview and FGDs in leprosy villages. A pilot study was conducted to test the data collection procedures and data collection tools. The questionnaire was pre-tested and revised accordingly.

The investigators in this study were trained in a health system research workshop, which was financially supported by The Netherlands Leprosy Relief (NLR).

RESULTS

General description of the leprosy villages under the study

Anqiu leprosy village, one of the biggest leprosy villages in Shandong province, was built in 1958. The villages are 17 km from the county town and near the main road, from which vehicle access is easy, even in the raining season. More than 300 leprosy patients used to live in the village (the main purposes being for isolation and regular treatment) before the 1970s. As the prevalence of leprosy declined and the policy of treatment changed to outpatients treatment, the number of patients living in the village has been reduced to 54 at present. Anqiu Skin Disease Control Station (formerly called the Leprosy Control Station) was responsible for the management of the village. The village committee, consisting of 4 members of the villagers, managed daily and productive activities.

Feixian leprosy village, located at the bottom of a hill, was built in 1959. The village is 20 km from the county town. The mountain road from the main road to the village (5 km) is bad, especially in the raining season. The last part of the road (2 km) is worse and it is difficult for a vehicle to drive in. More than 100 patients used to live in the village; the population is nine ex-patients at present. Feixian Leprosy Control Station (combined with TB control programme and formed into a general hospital in 2001) was responsible for the management of the village. Two staff from the hospital lived nearby (1 km) and visited the village twice a week. An old person with higher educational background was appointed by the hospital to manage the daily activities in the village.

Dongying leprosy village is 35 kilometres away from the county town and directly managed by the Dongyiny Institute of Dermatology (prefecture level). The village was built in 1958 and has moved twice since then. The first move in 1968 was because the original leprosy village was too near to the county town, and the exploitation of an
oilfield in the area of the leprosy village in 1974 caused the second move. Since leprosy was non-endemic in Dongyiny prefecture, about 50 leprosy patients used to live in the village and only 10 ex-patients are in the village at present. Vehicle access into the village along a side road is easy. One staff member from the institute was responsible for the management of the daily activities of the village.

**General description of the study population and stigma**

**Demographic characteristics of the study population**

In total, 49 ex-leprosy patients were interviewed, 42 (86%) males and 7 (14%) females. The mean age of the 49 ex-patients was 65 years, ranging from 49 years to 83 years. Out of the 49 ex-patients 11 were married, 11 were divorced, three were widowed and 24 were single. Only 17 people had family numbers. Thirty-six (75.5%) ex-patients had multibacillary (MB) leprosy and 43 (88%) people had visible deformity. Out of the 43 people with grade 2 disabilities, the mean WHO EHF score was 6.4. The demographic characteristics and the disability status of the 49 people in the three leprosy villages are presented in Table 1.

**Table 1** Demographic characteristics, type of leprosy and disability status of the 49 ex-leprosy patients interviewed in three leprosy villages, Shandong province

<table>
<thead>
<tr>
<th></th>
<th>Anqiu (n=30)</th>
<th>Feixian (n=9)</th>
<th>Dongying (n=10)</th>
<th>Total (n=49)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (mean + sd)</strong></td>
<td>64.50±9.95</td>
<td>66.11±8.25</td>
<td>65.10±9.64</td>
<td>64.92±9.43</td>
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<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>26</td>
<td>7</td>
<td>9</td>
<td>42</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td><strong>Schooling (Years)</strong></td>
<td>3.4</td>
<td>3.5</td>
<td>2</td>
<td>3.3</td>
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<tr>
<td><strong>Marital status</strong></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Married</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Single</td>
<td>16</td>
<td>3</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>Divorced</td>
<td>10</td>
<td>1</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td><strong>Type of leprosy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MB</td>
<td>21</td>
<td>6</td>
<td>9</td>
<td>36</td>
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<tr>
<td>PB</td>
<td>9</td>
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<td>13</td>
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<td><strong>Grade-2 disability</strong></td>
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<tr>
<td>Yes</td>
<td>28</td>
<td>7</td>
<td>8</td>
<td>43</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>6</td>
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</tbody>
</table>

**Stigma**

As to the other studies where stigma against leprosy is very common, out of the 49 patients, 19 (16 males and three females) were married at diagnosis. Of the 16 male married ex-patients, 12 were divorced. The most common reason for divorce was fear
of infection. One patient’s wife separated from him and another patient’s wife asked him to stay in the leprosy village for treatment. Apart from the spouses, 14 ex-patients said their family members had abandoned them, and two ex-patients said their brothers asked them to leave the family home after the diagnosis of leprosy. The commonest reason was fear of infection (13 ex-patients), and feeling stigmatized in the villages (3 patients). Another four ex-patients said that their family members also were stigmatized by the people in the community. Some remote relatives of ex-patients had also changed attitude towards them after the diagnosis of leprosy was made.

Out of 49 ex-patients interviewed, 30 ex-patients said the community members had stopped all contacts with them since the diagnosis of leprosy was made. One patient’s neighbour even moved house. Six ex-patients said they experienced denial and rejection by the community members. Ten ex-patients said their community members were afraid of them. One patient lost his job.

Some patients also stigmatized themselves. They did not want to go to public places, or avoid contact with other people. Some ex-patients did not want to visit their family because they tried to avoid their family members and relatives being stigmatized within the community.

Of the 14 ex-patients who had families living outside the leprosy villages, nine patients’ family members had visited them in the last year, mainly sons and daughters visited their farther or mother. Among the 49 ex-patients, 28 patients’ relatives visited them last year, mainly siblings. Only three ex-patients were visited by more remotely relatives. Slightly over half of the ex-patients went to visit their families or relatives in the past year. Nine ex-patients expected their family members to visit them more frequently, or desired their relatives to keep a close relationship with them. They hoped eventually to be accepted by their relatives and communities.

**Resources and needs**

*Anqiu leprosy village*

**Houses** Most houses in the villages were constructed with bricks in early 1970s and some houses were reconstructed in 1998 and 2004, respectively. General speaking, the condition of the houses was good, with two or three persons per room (30 m²). Tap water was near the houses and electricity was available. The village had a big common room with TV set for entertainment and meetings. There was a common kitchen in the village in which bread was made for the people and boiling water was provided. There were also some storage houses for productive machines and storage of agricultural products. The two toilets in the village required squatting, which was not convenient for the people with foot and leg disability. Some patients complained that it was difficult to clean themselves with a hand stump after defecation.
Land and production Anqiu leprosy village had access to 240 acres of fertile land, which belonged to the county government. As the number of people in the village declined, the age of the people increased and the disability status got worse, 180 acres of the land had to be rented to the farmers in the neighbouring villages at 100-150 RMB per acre. The yearly rent of 20,000 RMB was collected as the common income of the village. The main productive tools included one tractor, one grain-off machine and one grass mower, which were used for common fieldwork, and other collective tools such as hooks and hoes.

Economic situation and needs The county government had stopped financial support for ex-patients living in the village since 1991. Everyone was then required to seek financial support from his original village. However, it was becoming more difficult for most people in the leprosy village to ask for money or food from their original villages, due to the poor financial condition in rural areas of the county. Out of 30 ex-patients interviewed, only 23 had received money from their original villages in the last year. The money requested varied from 300 RMB to 4150 RMB, with an average of 1597 RMB, accounting for 64.3% of their yearly income. For the less disabled who still could work in the field, life was easier than for those who were older and with severe disability, if the financial support from their original villages was limited. In the past few years, an economic rehabilitation programme has been initiated in the village, with pig raising. This has given the village a net income of 15,000 RMB per year. One-fifth of the income was paid for the animal keeping. The common income of the village served for the payment of electricity, water and common affairs, as well as for the subsidies of the members of village committee. Generally, the income for the ex-patients living in the village accounted to 565-4715 RMB per capita in the last year, with an average of 2421 RMB (yearly income per capita in rural area was 4320 RMB in 2004). Some patients planted vegetables in the garden, but all the patients had to buy meat and other living necessities, using their own income.

Most patients interviewed (22/30) expected to increase their living standard. Half of them with an income of 1802 RMB thought that the income was not enough to cover their needs. Out of these 15 patients, four female patients with an average income of 2175 RMB thought their incomes were not enough. The expected yearly income of the 15 patients was 2846 RMB on average, while the expected yearly income of the four female patients was 3087 RMB on average.

Clothes and blankets Most clothes and blankets originated from government’s support and other donations, such as Leprosy Day. Out of the 30 patients interviewed, 24 said they had to buy clothes themselves; eight patients said they also received support from their families and other relatives for their clothes and blankets.

Medical care and needs The village had a small pharmacy with common drugs, but the people had to pay for medication. The head of the village was the unpaid manager.
of the pharmacy. One ex-patient, who was trained for a short period of time, could deliver the drugs, and give intramuscular injections and even drips for mild health problems of people in the village. For major health problems the patients had to be referred to the township hospital, which was 5 km from the village.

Out of the 30 ex-patients interviewed, 29 said that their medical expenditure in the last year was 872 RMB on average, ranging from 100 RMB to 4000 RMB. The medical expenditure among 14 ex-patients with mild health problems last year was 403 RMB on average, accounting for 15.8% of their yearly income, while the medical expenditure among 15 ex-patients with severe diseases was 1310 RMB on average, accounting for 57.17% of their yearly income. Twenty of the 30 ex-patients said they needed more money to cover medical costs, especially for those with severe health problems in the last year.

**Feixian leprosy village**

**Houses** The houses were built with bricks and stones in 1960 and 1972. Some of the houses were damaged and in a bad condition. Since the number of the ex-patients in the village was less, each person was living in one room without electricity. Water came from a bump well. There was no common room for entertainment and meeting. One person ran a common kitchen and provided steamed bread only.

**Land and production** The leprosy village had 66 acres of mountainous land that was not particularly fertile. Sixty-four acres were rented out to a contractor who re-rented the land to farmers in the neighbouring villages or the ex-patients in the leprosy village. The rent varied from 30 to 150 RMB per acre, depending on the fertility of the land. It was, however, collected by the hospital. The ex-patients only planted 2 acres as main source of vegetables. There were no cooperative productive activities in the village.

**Economic situation and needs** The county government allocated 20,000 RMB to the hospital for the people living in the village. This amount of money was re-allocated by the hospital to the ex-patients. In the year 2004, each ex-patient received 1152 RMB on average, including a medical care fee. Four people also had some additional income from other sources. Only one person who was less disabled got 500 RMB from his farming and other business.

The main food was steamed bread made of wheat flour, which was allocated by the hospital to the people in the village. The monthly food was 15 kg of wheat flour per person. Out of nine people interviewed only one person said the food was not enough. He needed 25 kg per month.

Out of the nine ex-patients interviewed, seven ex-patients said that their income was low and could not cover their needs for living. The amount of the money requested was 1974 RMB per year on average, ranging from 1689 RMB to 2360 RMB (yearly
Clothes and blankets  The clothes and blankets in this village were mainly from local government and social support through the hospital. However, seven out of nine ex-patients said their clothes and blankets were not enough and they had to buy more.

Medical care and needs  There was no pharmacy in the village. Two medical staff visited the village twice a week or on call. One staff member was living 1 km away from the village. During the visits, she brought the ordered drugs from the hospital to the ex-patients according to their health problems. For severe diseases, the ex-patients had to pay for the costs by themselves if they had to get treatment in general hospital. Out of the nine ex-patients interviewed, seven patients who had common diseases were treated in the village, while two patients who had severe diseases paid for their medical costs in the county general hospital. The medical expenditure of the two patients was 1300 RMB on average, mainly coming from the support of their families.

Dongyin leprosy village

Houses  The original old houses were abandoned due to their poor condition. A block of new houses was rebuilt by the institute of dermatology for the patients last year. Each person had his/her own room (20 m²) with a separate kitchen. There was no common room for gathering together, but one room was used for TV. Electricity was available. There was no water supply because the water underground was too salty to drink in the area. Each week, the water was sent to the village by the institute and kept in vats for use.

Land and production  The 140 acres of land in Dongyiny leprosy village were salt-rich, but it was good for the plantation of cotton and corn. As in other two leprosy villages, 138 acres of land were also rented to the farmers of the neighbouring villages. The rent was collected by the institute of dermatology. Two less disabled ex-patients only planted two acres of land.

Economic situation and needs  The income of the patients in Dongying leprosy village was low, ranging from 900 RMB to 3460 RMB, with 1523 RMB per year on average (yearly income per capita in the rural area was 4204 RMB in 2004). The main income was from the government and the Institute of Dermatology. Only two ex-patients who had less disability could get some income from farming. Out of 10 patients interviewed, five said that their incomes were not enough. They estimated that their monthly income was only 1326 RMB.

Each patient got 200 kilograms of wheat flour per year. Out of the 10 patients interviewed only two patients thought their food was not enough. They said they needed at least 270 kg per year. One patient who was less disabled was asked to take care of those who could not care for themselves, e.g. by cooking and cleaning.
Clothes and blankets Most clothes and blankets were from the government (through the Institute of Dermatology). Out of the 10 patients interviewed, five patients said they had to buy clothes and one patient said he needed family support to do so.

Medical care and needs There was a small pharmacy in the village with some common drugs. One ex-patient who was trained by the Institute of Dermatology was responsible for dispensing the drugs. One medical staff visited the village every day to check for health problems and management of the daily activities in the village at the same time. In case of emergency, the patient could be transferred to the general hospital. The medical costs in the village and for the emergency would be paid by the institute. However, if ex-patients sought medical care by themselves, they bore responsibility for the medical expenditure.

Out of the 10 patients interviewed, two patients were not satisfied with the medical services in the village. The main reason was that the drugs kept in the village pharmacy of the village could not meet the needs of their health problems. They thought the institute should cover all the medical costs for their health problems. In the interview, five ex-patients expected that their disability should be cared for, in particular, one patient with bad vision who hoped to maintain his remaining vision, so that he could continue to take care of himself in daily activities.

Information generated from focus group discussions

In the FGD section, we explored the ex-patients’ current life, their expectations of life, how to improve their life in future and the opinions by the ex-patients, medical staff and government officials on adjustment of the leprosy villages in future (see Appendix).

For the first question only one FGD section with five ex-patients was organized in Anqiu leprosy village because there were only a few ex-patients in the other two leprosy villages. It was said by the ex-patients that their current life was satisfying. Food and clothes were provided, people in the village did not feel stigmatized, and a good relationship was maintained with the general population in the neighbouring villages. All the people were organized by the village committee to help each other. Regarding this question, all the medical staff in the three institutions and the government official in the two counties expressed similar opinions to those of the ex-patients. In contrast to the ex-patients, they believed that basic medical care was provided. Some of them even said the current life in the leprosy villages stood at middle-level, compared with the general population, and was much better than that of ex-patients living in their original communities.

As to the future, the main issue was that ex-patients worried about their life in future because there was no government support to the village. As average age increased, and disability became more progressive, and because it would become more difficult
to ask for donations from their original communities due to the poor local economic situation, continued support would be necessary. The ex-patients raised questions regarding who would take care of them in future years. Medical care in particular was a cause of concern, because with increasing in age, apart from the health problems related to leprosy and disability, other health problems would arise. Therefore, the cost for medical care would increase. Furthermore, when most people in the village became old it would be impossible to take care of themselves, in terms of cooking and day-to-day living, and even going to the toilet.

Apart from the medical staff in the three institutions, the government officials in Anqiu and Feixian counties were also solicitous about the issue, the medical staff in Dongyiny Institute of Dermatology worried about the medical care in general health services because medical staff in general hospitals did not like to work with patients whose disability was caused by leprosy. The government official in Feixian further mentioned that it was difficult to obtain and invest financial support for the leprosy village for the installation of electricity and water supply because only a few ex-patients lived in that leprosy village, in spite of the current poor road condition and lack of electricity and tap water.

As to the future of the leprosy village, the participants in Anqiu leprosy village expressed a strong request that their life and care should be the responsibility of governments in order to ensure social security for people suffering from leprosy. They said it would be desirable to have a medical doctor visit the village more frequently to take care of their health problems. Another option for the care of the people in the village would be to recruit some younger people affected by leprosy to the village so that the younger ones could take care of the elderly. This would need government policy support.

The medical staff maintained that the solution for solving the current problems of the people living in leprosy villages would be a relevant policy generated by government (ideally from central government or provincial government) in order to ensure the necessary financial support. The care for the people in leprosy village also needed support from social bodies. Minimization of stigma among the general population would be helpful in integration of the people affected by leprosy into the community. Some elderly ex-patients could be cared for in a home for the elderly, since the number of the people affected by leprosy was already so small.

The government official suggested that the care for the people living in the leprosy village should be the responsibility of society as a whole, including governments at different levels and other social bodies, especially charity organizations. The money could be allocated from provincial, county and township governments in a certain ratio. Integration of medical care for ex-leprosy patients into the local cooperative medical care system should be considered.
Concerning the main question, the adjustment of small leprosy village, the participants in the FGD of Anqiu leprosy village agreed with the idea. They also agreed to accept other ex-patients from other leprosy villages to live in their village. This opinion was confirmed by the individual interviews; 40 out of 49 ex-patients agreed with the combination. The only thing that troubled them was that it would be inconvenient to ask support from their original community, if they were living far away from their home town. In addition, they feared inconveniences in visiting relatives and a reduction in their standard of living. When we asked where the patients would prefer to go if the leprosy village was to be closed, the information referenced from individual interviews was that about three-quarters of the 49 ex-patients did not want to go back to their original communities and even to their own homes. The reason given was the fear of stigma (23/33), lack of ability to care for themselves and nobody to take care of them (5/33), and no guarantee of support (2/33).

Some medical staff agreed with the combination of leprosy villages, but others did not. The reason for disagreement was that once the leprosy village was closed, they would lose their job. They had been working with leprosy for decades, and it would be difficult for them to adapt a new job. The opinion regarding to the combination of leprosy villages was controversial among government officials as well. Some of them thought it was a good idea. However, they felt that financial support should be allocated from governments at different levels. On the other hand, some officials argued that the implementation of the combination of leprosy villages was not easy. It needed strong government commitment, more investment from the government in the beginning, and allocation of more manpower. The key issue in combining leprosy villages was the money; for example, who would pay for the construction of a large leprosy colony? Who would pay for maintaining the budget for that village? And who would pay for the living, care and medical care? Government officials thought that it was impossible to implement the adjustment without answering these questions.

DISCUSSION

Following the decline in the prevalence of leprosy and the implementation of the integration of leprosy control programme into general health services in many counties of the world, many leprosaria and leprosy shelters have been closed, including in China. However, little information on how to deal with these leprosy settlers and the people who used to live in these shelters is available. In our previous paper, we introduced the historical and present situation of the people living in the leprosaria/villages in Shandong province, which was representative of the whole picture in China.

With similar findings in our previous survey, the age of those people living in the three selected leprosy villages is high, with a mean of 65 years. The marriage rate is low; the majority of ex-patients do not have families and the vast majority has visible
deformity and low productive ability. These aspects reflect the need for the continuing support of the people living in the villages. The living standard in the three leprosy villages varies, reflecting the inconsistent support system for the leprosy villages in Shandong. Historically and even today, the support for the leprosy control programmes and the care for the ex-patients living in leprosy villages in different areas is the responsibility of local governments. Therefore, the level of support depends on the local social and economic development on the one hand, and the degree of concern of the local government officials on the other hand. Advocacy of government officials for support of ex-leprosy patients is a vital task for the leprosy control programmes in different areas, in order to improve the present situation.

At present, the basic food and clothes for the people in leprosy villages of Shandong province can be secured by local governments (managed by leprosy control programmes) and supplemented by communities and patients’ families and relatives. However, the quality of care for those disadvantaged people is of great concern. As the people become older and the deformities deteriorate, as expected in near future, many of the ex-leprosy patients will lose the ability of self-care in their routine daily activities, such as cooking, washing, cleaning, eating and even going to the toilet. For leprosy villages with more ex-patients, the people can help each other, but for the small villages it will be more difficult because most people are disabled and living conditions are less satisfying than the leprosy villages with few people, especially for villages, which are located in remote and isolated areas. How to deal with the problem has become the top priority of leprosy control programmes at different levels in the province.

Medical care is another important issue. In the individual interviews, a majority of the people complained about the shortage of money for medical care. In current circumstances, as with all the farmers in China, there is no security for medical care of the people living in leprosy villages. The policy is that the ex-leprosy patients in leprosy villages have to pay for their own medication, either from their living allowances allocated by government or from their income. This is very difficult for the people with low income if they also are old and have severe disability. The political leaders and medical staff in leprosy control programmes should have sympathy towards those ex-leprosy sufferers, and whenever possible, increase the budget for medical care to meet their needs. Apart from this, advocacy of governments at different levels should be made, especially at top level, to formulate a policy for the medical care of the ex-leprosy sufferers living in leprosy villages.

Stigmatization towards leprosy sufferers, especially the disabled, is very common and can be found almost everywhere around world. It can strongly influence the patient’s life including partners’ relationships, family affairs, personal relationship within a community and marriage. This negative influence not only exists among the leprosy sufferers themselves, but often also involves in the family of a leprosy patient, and even the third generation. From this survey, it can be concluded that many
sufferers of leprosy were forced to stay in leprosy villages by their spouses, parents, siblings and even remote relatives after they were diagnosed as having leprosy. Furthermore even when they were cured, some have to stay in the isolated villages and have difficulty in going home or visiting their families due to the stigmatization they are facing. This discrimination against leprosy is deeply engrained, and has a fundamental impact on the integration of leprosy control programme into the general health services and leprosy sufferers into the community; it is the main reason for the dependency of the people affected by leprosy.

In our previous report on the role of leprosy villages/leprosaria we suggested an option in solving the current problem, i.e. to combine some small leprosy villages into a few remaining leprosaria/big leprosy villages in which the living condition and facilities are better than in a leprosy village located in an remote area and with a few disabled ex-patients, in order to increase the cost-effectiveness. However, some obstacles may exist, although in general most leprosy sufferers, the medical staff and governmental officials agree with the idea. The key issue is to advocate government at national level, or at least at provincial level to formulate a policy and to allocate a specific budget for the combination. This can be further supported by local governments. Only in this way, can people affected by leprosy be better cared for from the point of view of equality of social development, and resources be used more effectively. The leprosaria/leprosy villages can thus play a better role not only for ex-leprosy patients living in existing leprosy villages/leprosaria, but also for ex-leprosy patients isolated and rejected in the community.

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Appendix: Topics for focus group discussion (FGD)

Topics for FGD for the people affected by leprosy living in a leprosy village
1. What do you feel the life here is like?
2. What is your expectation of your life? (in terms of care, house, medical care, food, social communication, etc.)
3. How to improve your life in future?
4. If government decides to close the village, what is your opinion?

Topics for FGD for medical staff
1. What do you think of the life of the people affected by leprosy in the leprosy village?
2. What are the major problems for the people affected by leprosy in the leprosy village?
3. How to improve the present situation faced by the people and the leprosy village?
4. If government decides to close the village, what is your opinion?

Topics for FGD for government officials
1. What do you think of the life of the people affected by leprosy in the leprosy village?
2. What role the government should play in management of the leprosy village?
3. If we suggest closing the village and moving the people affected by leprosy in the village to some other place, what is your opinion?
4. Do you have any suggestions to improve the present situation faced by the people and the leprosy village?