Role of leprosy villages and leprosaria in Shandong Province, People’s Republic of China: past, present and future

CHEN SHUMIN, LIU DIANGCHANG, LIU BING, ZHANG LIN & YU XIOU LU
Shandong Provincial Institute of Dermatology and Venereology, 57 Jiyan Lu, Jinan, Shandong, P.R. China 250022

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Summary In the late phase of the leprosy control programme in Shandong Province, People’s Republic of China, there are a few old and disabled ex-patients living in 54 leprosy villages/leprosaria. The small, and declining number of patients makes the running of these leprosy villages/leprosaria uneconomic. In this paper, we review the history and the role of leprosy villages/leprosaria in the care of leprosy patients and the control programme in Shandong province. We then analyse the present situation of the 643 people still living in these leprosy villages/leprosaria, using information collected from a questionnaire-based survey. Finally, we offer some suggestions and recommendations for policy makers and leprosy control managers, in order to improve the present situation and make better use of existing resources.

Introduction

The leprosy control programme started in 1955 in Shandong Province, using a vertical approach. After more than 20 years effort against this disease through intensive case finding, case holding, implementation of chemotherapy, first with dapsone monotherapy, and later with a combination of dapsone and rifampicin, the prevalence and incidence of leprosy declined significantly by the late 1970s and early 1980s. The process of elimination of leprosy was further facilitated by the introduction of multi-drug therapy (MDT) in 1986 province-wide. By the end of the year 2000, a total of 53,677 leprosy cases were registered, with only 122 cases on MDT. The profile of the epidemiology of leprosy and details of the leprosy control programme in this province have already been described elsewhere.1,2

Leprosy villages or leprosaria (called leprosy ‘settlements’ in many parts of the world) have played a unique role in the leprosy control programme in Shandong province. More than 80% of the total registered leprosy cases have been held in leprosy villages/leprosaria for variable periods of time. This has had both positive and negative impacts on the leprosy control programme in Shandong, perhaps reflecting the whole situation of leprosy control in China. In this paper, we review the development and the role of leprosy villages/leprosaria in

Correspondence to: Chen Shumin (e-mail: Chenshm@public.jn.sd.cn)
the leprosy control programme using data from historical records. We then analyse the present situation of leprosy villages/leprosaria, using the information collected from a questionnaire-based survey. Finally, we make some suggestions and recommendations for policy makers and programme managers, in order to improve the present situation and make better use of exiting resources.

History of leprosy villages/leprosaria in Shandong Province

LEPROSARIA

In 1918, the first leprosarium was established by American Leprosy Missions in Tongzhou county, with 60 beds. Up to 1942, a total of about 700 leprosy cases were admitted. From 1925 to 1936, four more leprosaria were opened, with a capacity of 200 beds, by missions from Britain, Germany and America (Jinan Leprosarium, 1925, Yanzhou Leprosarium, 1928, Qingdao Leprosarium, 1932 and Qingzhou Leprosarium, 1936). Apart from these leprosaria, several leprosy clinics were opened by foreign and Chinese missions in several places around Shandong. Unfortunately, we have been unable to find out how many leprosy cases were once cared for in these different institutions.

In 1951, 2 years after the foundation of New China, Shandong provincial government allocated considerable funds for the repair of the existing five leprosaria. The number of beds increased from 200 to 1050. In 1953, an additional leprosarium with 70 beds was opened by the Provincial Bureau of Health in Tongzhou County, specifically for government employees who suffered from leprosy.

Development of leprosy villages in Shandong

In the spring of 1956, a leprosy ‘resettlement’ was built up in a remote valley by local villagers in Junan County. Nine leprosy patients were forced to resettle in areas of land delineated for them to farm. The first leprosy village run by the government was established in Haiyang County in the winter of 1956. In February 1958, a meeting was held by the provincial bureau of health in Haiyang leprosy village. The experience that a leprosy village can be run by local people and subsidized by government, combining farm activities and medical treatment was recognized and extended into other parts of the province. In the same year, another 153 leprosy villages were established to accommodate 11,130 leprosy patients in the whole province. By 1959, with government financial support, the number of leprosy villages increased to 180, with 8189 rooms and 17,125 patients, accounting for 72.16% of the total of 23,731 cases in the province. Among them most were classified as lepromatous. In 1960, more than 18,000 leprosy cases were held in these leprosy villages/leprosaria, with an isolation rate of 77.1% of the total leprosy cases registered.

From the 1970s onward, as the prevalence and incidence of leprosy declined, some leprosy villages were closed or small villages within one county were combined. As the result, the number of villages was reduced to 114, and later, to 80 in the 1980s. With the introduction of MDT into the whole province in 1986, there were some changes in case holding policy based on the change from patient isolation to MDT isolation; change from life-long dapsone monotherapy to fixed period MDT; change from treatment in leprosy institutions to treatment in community and improved approaches to rehabilitation. Thereafter, more leprosy villages and two leprosaria were closed, leaving 57 leprosy villages and
leprosaria in 1994 and 54 in 52 counties/cities at present. By the end of 1994, about 80% out of 53,241 leprosy cases registered in the province once lived in leprosy villages/leprosaria for periods varying from several months to more than 40 years.  

**Role of leprosy villages/leprosaria**

The basic idea of the leprosy village in Shandong was to isolate leprosy patients to stop the transmission of the disease, because leprosy patients were treated with dapsone monotherapy for life and considered incurable in the 1950s and 1960s. Some positive and negative impacts of leprosy villages/leprosaria on the leprosy control programme in Shandong can be summarized as follows.

**Positive Roles**

- **Better care for leprosy patients.** The living standard of patients living in leprosy villages and leprosaria was higher than those living in the community before the 1980s, when the country was at very low development stage. The patients’ income was from donations from their original communities, whilst farm products, food and other living necessities were subsidized by the government. In addition, some complications of leprosy such as leprosy reactions, neuritis and drug reactions, and other health problems could be better dealt with in patients living in leprosy villages/leprosaria than those living in the community. Reconstructive surgery for deformities could be more conveniently performed in leprosy villages as well, because most leprosy control stations were also located nearby before the 1980s.
- **Less stigmatization in leprosy villages and leprosaria.** Perhaps contrary to expectations, patients living in leprosy villages and leprosaria felt that they were less stigmatized than when they lived in the community.
- **More regular treatment.** During dapsone monotherapy in the 1950s and 1960s and combined therapy of dapsone with rifampicin before the introduction of MDT, supervision of treatment for the patients living in the communities was not compulsory, while for the treatment of the patients living in the leprosy villages and leprosaria, daily supervision of the medications was required by the programme. As a result, the treatment of patients living in the leprosy village was more regular than those living in the community, and this may explain their lower relapse rate compared to those living in the community.  

- **Interruption of the chain.** This is a controversial issue. Although the exact route of transmission of leprosy is still not understood, it is generally believed that human beings are considered as the major host and reservoir of *Mycobacterium leprae*. Therefore, it was thought that isolation of leprosy patients could play a role in stopping the transmission of the disease.
- **Provision of shelter for the homeless and those exiled from their communities.**

**Disadvantages**

- **Increase of social stigma.** Infectiousness and disability are the major causes for the prejudice and stigma against leprosy. Isolation of leprosy patients in leprosy villages/leprosaria gives an impression to the public that leprosy is infectious, thus creating fear and
stigma towards leprosy, and finally rejection by the public. Self-stigmatization of patients also plays an important role in keeping them in these institutions.

- **Loss of self-esteem and dignity.** Once a patient lived in a leprosy village, he/she would be fed and supported by the community and local government, even though he/she did not do any work in the leprosy villages/leprosaria. Gradually, they lost dignity and self-esteem, and became dependent. Even today, many people affected by leprosy in China still strongly believe that community and government have responsibility for them, no matter what their social and clinical state may be.
- **Less cost-effective.** As the number of cases living in leprosy villages has reduced in the late phase of the leprosy control programme, it is less cost-effective to maintain them including logistic supply and repair of the houses. Especially since political and economic reforms took place in 1980s, government support for leprosy villages and leprosy control in general has been reduced.

### Present situation of the people affected by leprosy in leprosy villages/hospitals

At present, there are 51 leprosy villages and three leprosaria located in 52 counties in Shandong, in which only 643 people affected by leprosy are living. There are 577 males and 66 females. As shown in Table 1, the majority of the people (67.7%) are over 60 years old, with an average of 64.6 ± 9.8 years. Comparatively, more women are illiterate (77.3% in females versus 54.6%, in males \( P < 0.01% \)). Only 32.8% of the people are married (some couples are both affected by leprosy and married in leprosy villages). There are more men

<table>
<thead>
<tr>
<th>Variables</th>
<th>Males, ( n = 577 ) (%)</th>
<th>Females, ( n = 66 ) (%)</th>
<th>Total, ( n = 643 ) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (mean)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \leq 50 )</td>
<td>64.5 ± 9.5</td>
<td>65.7 ± 12.3</td>
<td>64.6 ± 9.8</td>
</tr>
<tr>
<td>( \leq 60 )</td>
<td>53 (9.2)</td>
<td>10 (15.2)</td>
<td>63 (9.8)</td>
</tr>
<tr>
<td>( \leq 70 )</td>
<td>136 (23.6)</td>
<td>9 (13.6)</td>
<td>54 (8.4)</td>
</tr>
<tr>
<td>( &gt; 70 )</td>
<td>236 (40.9)</td>
<td>23 (34.8)</td>
<td>259 (40.3)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>315 (54.6)</td>
<td>51 (77.3)</td>
<td>366 (56.9)</td>
</tr>
<tr>
<td>Primary school</td>
<td>235 (40.7)</td>
<td>15 (22.7)</td>
<td>250 (38.9)</td>
</tr>
<tr>
<td>Secondary and high school</td>
<td>27 (4.7)</td>
<td>0 (0.0)</td>
<td>27 (4.2)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>164 (28.4)</td>
<td>47 (71.2)</td>
<td>211 (32.8)</td>
</tr>
<tr>
<td>Single/divorced/loss of spouses</td>
<td>413 (71.6)</td>
<td>19 (28.8)</td>
<td>432 (67.2)</td>
</tr>
<tr>
<td><strong>Direct relatives</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nil</td>
<td>315 (54.6)</td>
<td>16 (24.2)</td>
<td>331 (51.5)</td>
</tr>
<tr>
<td>Children/parents/spouses</td>
<td>262 (45.4)</td>
<td>50 (75.8)</td>
<td>312 (48.5)</td>
</tr>
<tr>
<td><strong>Living standard (RMB/month)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \leq 100 )</td>
<td>369 (64.0)</td>
<td>43 (65.2)</td>
<td>412 (64.5)</td>
</tr>
<tr>
<td>( \leq 200 )</td>
<td>158 (27.4)</td>
<td>19 (28.8)</td>
<td>177 (27.5)</td>
</tr>
<tr>
<td>( &gt; 200 )</td>
<td>50 (8.7)</td>
<td>4 (6.0)</td>
<td>54 (8.4)</td>
</tr>
</tbody>
</table>

\( * P < 0.05. \)  
\( ^{b} \) Including children/parents and spouses.
Table 2. Self-care, limitation of daily activity and productive activity, and restriction of participation among 643 people affected by leprosy in leprosy villages/leprosaria, Shandong Province

<table>
<thead>
<tr>
<th>Variables</th>
<th>Males, n = 577 (%)</th>
<th>Females, n = 66 (%)</th>
<th>Total, n = 643 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ability of self-care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very difficult</td>
<td>132 (22.9)</td>
<td>16 (24.3)</td>
<td>148 (23.0)</td>
</tr>
<tr>
<td>Difficult</td>
<td>233 (40.4)</td>
<td>22 (33.3)</td>
<td>255 (39.7)</td>
</tr>
<tr>
<td>No problem</td>
<td>212 (36.7)</td>
<td>28 (42.4)</td>
<td>240 (37.3)</td>
</tr>
<tr>
<td><strong>Daily activity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very difficult</td>
<td>186 (32.2)</td>
<td>23 (34.8)</td>
<td>209 (32.5)</td>
</tr>
<tr>
<td>Difficult</td>
<td>217 (37.6)</td>
<td>22 (33.3)</td>
<td>239 (37.2)</td>
</tr>
<tr>
<td>No problem</td>
<td>174 (30.2)</td>
<td>21 (31.8)</td>
<td>195 (30.3)</td>
</tr>
<tr>
<td><strong>Productive activity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very difficult</td>
<td>250 (43.3)</td>
<td>31 (47.0)</td>
<td>281 (43.7)</td>
</tr>
<tr>
<td>Difficult</td>
<td>215 (37.3)</td>
<td>24 (36.4)</td>
<td>239 (37.2)</td>
</tr>
<tr>
<td>No problem</td>
<td>112 (19.4)</td>
<td>11 (16.7)</td>
<td>123 (19.1)</td>
</tr>
<tr>
<td><strong>Participation in family affairs</strong>a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very difficult</td>
<td>86 (32.8)</td>
<td>18 (36.0)</td>
<td>104 (33.3)</td>
</tr>
<tr>
<td>Difficult</td>
<td>97 (37.0)</td>
<td>15 (30.0)</td>
<td>112 (35.9)</td>
</tr>
<tr>
<td>No problem</td>
<td>79 (30.2)</td>
<td>17 (34.0)</td>
<td>96 (30.8)</td>
</tr>
<tr>
<td><strong>Participation in social affairs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very difficult</td>
<td>291 (50.4)</td>
<td>38 (57.6)</td>
<td>329 (51.2)</td>
</tr>
<tr>
<td>Difficult</td>
<td>203 (35.2)</td>
<td>18 (27.3)</td>
<td>221 (34.4)</td>
</tr>
<tr>
<td>No problem</td>
<td>83 (14.4)</td>
<td>10 (15.2)</td>
<td>93 (14.5)</td>
</tr>
</tbody>
</table>

a Out of 312 people with family (including children, parents and spouses).

who do not have any direct relatives than women (P < 0.05). A total of 412 (64.5%) out of 643 people are living below the line of absolute poverty, according to the government standard in Shandong (≈ 100 RMB/month). As mentioned above, the money for the patients’ support varies from place to place and from person to person, because it is raised by the patients from their own villages and farm communities. Therefore, this support depends heavily on the local economic situation and the health condition of the patients. Since the vast majority of patients are from rural areas which are often less developed in Shandong, it is difficult for them to ask for money for their support. If this is the case, they can get a small amount of money from local governments for survival.

Most people in this group have some degree of difficulty in self-care and daily activity, which means that most people are dependent, with no difference between male and female. Less than 20% of the people are able to engage in productive activities. Not surprisingly, many people in this group have lost respect and dignity in their families (89.2%) and communities (85.6%) (Table 2). The self-assessment of health condition and disability grading of the people affected by leprosy are presented in Table 3.

Discussion

Leprosy is a unique disease of human beings, with a variety of social and economic dimensions due to fear and stigmatization. In the early stage of leprosy control programmes,
patients had to be treated for years, even for life. Therefore, in many parts of the world, leprosy patients were kept in institutions as permanent residents. In Shandong Province, as in China at large, they mainly engaged in agriculture and animal husbandry in these so called leprosy villages/leprosaria. As the number of cases in these institutions has fallen, and the age of these people increased, most of these abandoned people have lost their productive ability, due to ageing and a variety of disabilities due to leprosy. From the data given above, following points can be drawn:

1. There are only a few people in each leprosy village (12 people per village on average). It is becoming increasingly costly to maintain these villages, including paying for repairs to houses, payment for staff and other basic costs.
2. Most people are old (64-6 years on average) and are single with more than 50% of the people without direct relatives. The health condition and living situation of the most people living in these leprosy villages/leprosaria are poor.
3. Many people are dependent and need more support.
4. Most people (89.3%) have some kinds of visual deformity (WHO grade 2).
5. There is still some social stigma against leprosy, even for those who have been cured for a long time. A total of 211 (32.8%) married people or 48.5% people with direct relatives have to stay in leprosy villages/leprosaria. Two hundred and sixteen (69%) out of 312 people who have families have some problems in participation in family affairs and over half of them have difficulty in social participation.

In order to improve the present situation and better use of the existing resources, the following suggestions and recommendations will be made to policy makers and programme

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### Table 3. Health condition and disability among 643 people affected by leprosy in leprosy villages/leprosaria, Shandong Province

<table>
<thead>
<tr>
<th>Variables</th>
<th>Males, n = 577 (%)</th>
<th>Females, n = 66 (%)</th>
<th>Total, n = 643 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Major health problems</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>65 (11.3)</td>
<td>6 (9.1)</td>
<td>71 (11.0)</td>
</tr>
<tr>
<td>No</td>
<td>512 (88.7)</td>
<td>60 (90.9)</td>
<td>572 (89.0)</td>
</tr>
<tr>
<td><strong>Self assessment of health condition</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>73 (12.7)</td>
<td>7 (10.6)</td>
<td>80 (12.4)</td>
</tr>
<tr>
<td>General</td>
<td>189 (32.8)</td>
<td>25 (37.9)</td>
<td>214 (33.3)</td>
</tr>
<tr>
<td>Bad</td>
<td>315 (54.6)</td>
<td>34 (51.5)</td>
<td>349 (54.3)</td>
</tr>
<tr>
<td><strong>Disability grading</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual deformity</td>
<td>514 (89.1)</td>
<td>60 (90.9)</td>
<td>574 (89.3)</td>
</tr>
<tr>
<td>No visual deformity</td>
<td>63 (10.9)</td>
<td>6 (9.1)</td>
<td>69 (10.7)</td>
</tr>
<tr>
<td><strong>WHO grating scores</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–3</td>
<td>33 (6.4)</td>
<td>2 (3.3)</td>
<td>35 (6.1)</td>
</tr>
<tr>
<td>4–6</td>
<td>110 (21.4)</td>
<td>10 (16.7)</td>
<td>120 (20.9)</td>
</tr>
<tr>
<td>7–9</td>
<td>116 (22.6)</td>
<td>13 (21.7)</td>
<td>129 (22.5)</td>
</tr>
<tr>
<td>10–12</td>
<td>255 (49.6)</td>
<td>35 (58.3)</td>
<td>290 (50.5)</td>
</tr>
<tr>
<td><strong>Disability by sites</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye</td>
<td>378 (73.5)</td>
<td>47 (78.3)</td>
<td>425 (74.0)</td>
</tr>
<tr>
<td>Hand</td>
<td>462 (89.9)</td>
<td>55 (91.7)</td>
<td>517 (90.1)</td>
</tr>
<tr>
<td>Foot</td>
<td>434 (84.3)</td>
<td>55 (91.7)</td>
<td>489 (85.2)</td>
</tr>
</tbody>
</table>

* Including people with visual disabilities.
managers: (i) some form of leprosy village or leprosarium is still needed for those who are old and homeless, with or without disabilities; (ii) most leprosy villages/leprosaria should be closed. Those who have to stay in institutions can be moved to the remaining few leprosaria, in which the living condition and facilities are better than leprosy villages in general, in order to increase cost-effectiveness; (iii) the role of the leprosy village/leprosarium should be changed from resettlement of people affected by leprosy to a rehabilitation centre.

The main roles of leprosy village/leprosaria will be: (i) to act as a referral centre for difficult cases province-wide, such as patients with severe reactions or neuritis and the patients who need reconstructive surgery; (ii) to be a shelter for the homeless and elderly on an indefinite time basis (including those who are abandoned by the communities); (iii) to be a training centre for those who need special skills in physical and economic rehabilitation (not only for the people living in the leprosy village, but also for people living in the communities); (iv) to be a training centre for leprosy control workers.

The people living in the remaining leprosy villages/leprosaria can be categorized into the following groups, according to their problems and their needs, in order to provide better care: (i) those who are too disabled or too old to take care of themselves; some kind of care should be provided from the point of view of social equity and justice; (ii) those without or with minimal disability, who are able to do farming or other income generating work; an economic rehabilitation project should be initiated, to help them increase their economic empowerment; (iii) those with neither physical disability nor social problems; if their communities will accept them, life should be restored to normal as much as possible, with the cooperation of local governments (if this is not possible, they can stay in the rehabilitation centre).

In order to meet the needs of people affected by leprosy in leprosy villages, higher budgets should be allocated from provincial level to township level, including, where appropriate, donations from Non-Government Agencies. A multi-sectoral cooperation approach should be adopted to improve coordination between organizations, including those working with the disabled and in social affairs, and to provide better care and resources for the unfortunate people described in this study, some of whom have spent most of their lives in poverty and segregation.

Acknowledgement

We would like to thank all the staff working in the field for the collection of the data.

References