

Current situation of leprosy colonies/leprosaria and their future in P.R. China

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Summary

Objective To identify the current situation of leprosy colonies/leprosaria and make some recommendations for improving the quality of life of people affected by leprosy in China.

Methods A national survey using designed forms was carried out in 2004. The forms were filled in by local heads responsible for the management of leprosy colonies/leprosaria and sent to Provincial and National Centres for analysis.

Results China had 605 leprosy colonies/leprosaria with 555 active leprosy patients (on treatment) and 18,175 ex-patients (people affected by leprosy) living in them at the end of 2004. Among 18,730 patients and people affected by leprosy, 13,430 (71.7%) had grade 2 disabilities. Among those with visible disability, 6392 (47.6%) lost the ability to take care of themselves due to serious deformity. Because of a decrease in health workers working at leprosy colonies and a shortage of medical materials, the health care quality of these people was neglected. Most colonies/leprosaria were located at remote and isolated places with difficult transportation, and most buildings/houses were in danger of collapse because the colonies/leprosaria were built in the 1950's. Those affected by leprosy were in great need of help.

Conclusion The authors recommend that small, remote and isolated leprosy colonies should be closed. New leprosaria at District, Provincial or National levels should be established or some old leprosaria with good transportation should be reconstructed to house those affected by leprosy from closed leprosy colonies/leprosaria. The newly established or reconstructed leprosaria could act as centres for reference, training, rehabilitation and research on leprosy.

Introduction

In 1987, the Ministry of Health of PR China brought about four changes to the National Leprosy Control Programme: 1) a change from monotherapy to Multidrug therapy; 2) a change from isolation to community control; 3) a change from chemotherapy alone to a

combination of chemotherapy with rehabilitation; 4) a change from the efforts of leprosy workers alone to the coordinated efforts of the whole society. With these changes, leprosy control in China entered a new era.

In order to strengthen case-finding, a Station for Skin Disease/Leprosy Control and Treatment was established at every county town. Most leprosy health workers moved from remote and isolated leprosy colonies/leprosaria to the county station. Leprosy colonies were run by very few health workers and managers.

The new strategy changed the role of leprosy colonies/leprosaria. The running of leprosy colonies/leprosaria and the health care quality for patients was neglected, the buildings fell out of repair for many years and the function of providing medical services for leprosy patients was totally lost. Most leprosy colonies/leprosaria did not take in new patients any more due to the policy of treating patients at their homes. Leprosy colonies/leprosaria also did not provide services for patients with serious leprosy reactions, eye problems, side-effects of anti-leprosy drugs and other leprosy complications due to the lack of experienced doctors, necessary medical equipment and funds. Most leprosy colonies/leprosaria became collecting houses for those affected by leprosy.

From 2001, China's central government again carried out a health system reform on the pattern of disease control. The health system reform required that all units responsible for public health at or above county level should be merged into one unit named the Centre for Disease Control and Prevention (CDC). All Stations for Skin Disease Control and Treatment should be closed and form a department of leprosy control or be combined with the TB department in CDC.

Leprosy colonies/leprosaria, however, were not involved in this health system reform. They still ran in the old way and were not cost-effective.

Materials and methods

In order to identify the current situation of leprosy colonies/leprosaria clearly, and find feasible measures to solve their problems, we carried out a national survey on this issue in the annual report of the Leprosy Control Programme by each province at the end of 2004. Several forms were designed. All information about the various aspects of leprosy colonies/leprosaria – e.g. the number of leprosy colonies/leprosaria, the number of working staff, patients and ex-patients (people affected by leprosy) who still lived in the leprosy colonies/leprosaria, the disability condition among these patients and ex-patients and the number of healthy population who lived in leprosy colonies/leprosaria were included. The forms were filled in by local heads responsible for the management of leprosy colonies/leprosaria and sent to Provincial and National Centres for analysis.

We hoped this survey would provide useful information on leprosy colonies/leprosaria and enable recommendations to be made to policy makers and other interested organisations.

Results

THE NUMBER OF LEPROSY COLONIES/LEPROSARIA AND PEOPLE AFFECTED BY LEPROSY

At the end of 2004, the whole country of China (except Taiwan, Hong Kong and Macao) had 605 leprosy colonies/leprosaria (leprosy colonies are also called leprosy villages) with 555

active leprosy patients (on treatment) and 18,175 ex-patients (people affected by leprosy) living in them. Among these leprosy colonies/leprosaria, 18 were leprosaria at Provincial level, 58 were leprosaria at District level, and 529 were leprosy colonies (villages) at County level. The total number of medical and administrative staff was 5740. Among them, 1115, 1795 and 2830 were working at leprosy colonies /leprosaria at Provincial, District and County level, respectively. Among the 18,175 ex-patients living in leprosy colonies/leprosaria, 1578, 2643 and 13,954 were living in leprosy colonies/leprosaria at Provincial, District and County level, respectively. (Tables 1,2,3).

On average each Provincial leprosarium had 61.9 staff, 11.9 active patients and 87.6 ex-patients. Each District leprosarium had 30.9 staff, less than one active patient and 45.6 ex-patients. Each leprosy colony at County level had 5.3 staff, less than one active patient and 26.4 ex-patients.

DISTRIBUTION OF LEPROSY COLONIES / LEPROSARIA

There were 18 Provincial leprosaria which were distributed among 14 Provinces. They were mainly located in the west and the north of China, for example in Liaoning, Jilin, Hebei, Gansu Shaanxi, and Xinjiang, where leprosy prevalence was low. There were 58 District leprosaria distributed in Provinces with high leprosy prevalence in the past or currently. These District leprosaria were located in the south, east and southeast of China. Leprosy colonies at County level were almost all located in the south and southeast of China, for example in Yunnan, Sichuan, Guizhou, Guangdong and Guangxi where leprosy prevalence is still a little higher than in other Provinces. In the coastal Provinces in the east of China, leprosy prevalence was once very high but is now significantly decreased, for example in Jiangsu, Zhejiang and Shangdong.

Table 1. Leprosaria at Provincial level in 2004 in PR China*

Provinces	No. of leprosaria	Number of staff	Number of active patients hospitalised	Number of people affected by leprosy living at leprosaria
Hebei	1	93	24	25
Liaoning	1	104	5	70
Jilin	1	20	0	41
Shanghai	1	208	0	81
Zhejiang	1	11	3	119
Henan	1	50	18	10
Guangdong	1	58	2	81
Guangxi	1	75	18	190
Hainan	1	52	10	225
Tibet	1	20	0	20
Shaanxi	3	191	115	536
Gansu	2	59	0	103
Qinghai	2	98	19	42
Xinjiang	1	76	1	35
Total	18	1115	215	1578

* Provinces without leprosaria at Provincial level were not included.

Table 2. Leprosarium at District level in 2004 in PR China*

Provinces	No. of leprosaria	Number of staff	Number of active patients hospitalised	Number of people affected by leprosy living at leprosaria
Fujian	5	381	9	228
Jiangsu	5	190	0	142
Zhejiang	3	6	0	109
Ahhui	3	37	0	143
Jiangxi	3	222	6	179
Shandong	7	43	2	116
Hubei	5	342	4	132
Hunan	3	37	6	55
Guangdong	11	378	14	913
Guangxi	6	62	1	151
Hainan	2	24	0	178
Guizhou	2	40	0	126
Yunnan	3	33	1	171
Total	58	1795	43	2643

*Provinces without leprosarium at District level were not included.

DISABILITY AMONG PEOPLE AFFECTED BY LEPROSY LIVING IN THE COLONIES/LEPROSARIA

Among the 18,730 people affected by leprosy living in colonies/leprosaria, 13,430 (71.7%) had grade 2 disabilities. The highest rate of 95.1% of grade 2 disability was found in the Jilin Provincial Leprosarium located in the north of China. Among 13,430 cured patients with

Table 3. Leprosy colonies (villages) at County level in 2004 in PR China*

Provinces	No. of leprosy colonies	Number of staff	Number of active patients living in colonies	Number of people affected by leprosy living in colonies
Fujian	17	73	6	198
Shanghai	1	3	0	17
Jiangsu	34	91	4	1702
Zhejiang	9	14	5	256
Anhui	14	40	14	388
Jiangxi	59	330	16	755
Shandong	43	119	3	467
Hubei	31	102	6	537
Hunan	32	250	20	495
Guangdong	56	463	42	2431
Guangxi	24	38	8	353
Hainan	11	35	4	549
Chongqing	15	45	22	86
Sichuan	65	837	75	1993
Guizhou	36	237	50	1343
Tibet	2	7	0	11
Yunnan	80	146	22	2373
Total	529	2830	297	13954

*Provinces without leprosy colonies at county level are not included.

grade 2 disability, 6392 (47.6%) had lost the ability to take care of themselves due to serious deformity. They needed other people to attend to them daily. The main problem identified in leprosy colonies/leprosaria was the poor quality of life. Most leprosy colonies/leprosaria were located in the undeveloped mountainous areas in the southeast and west of China. Because of their grade 2 disability and their age (60–65 years on average), these people could not work to earn money. Most people affected by leprosy living in the colonies/leprosaria led a very poor life (see Table 4).

POOR QUALITY OF HEALTH CARE

Due to decreasing numbers of health workers working at leprosy colonies and a shortage of medical materials, the quality of health care was neglected. Many people suffered from serious foot ulcers, eye problems and other leprosy-related complications and could not get adequate treatment. Some people only received a little dressing and ointment to manage their ulcers and eye problem themselves. Thankfully some NGOs in Macao and Hong Kong and from some foreign countries provided a great deal of support to those affected by leprosy. They built houses, supplied tap water and electricity, provided dressings and drugs and even sent volunteers to work in the colonies.

THE ISOLATED SURROUNDINGS AND THE DILAPIDATED BUILDINGS/HOUSES IN COLONIES/LEPROSARIA

Due to the isolation policy for leprosy control in the middle of the last century, most leprosy colonies/leprosaria had been established in remote places, such as an isolated island, a beach or halfway up a high mountain usually with poor transportation. Some leprosy colonies at County level had very few people affected by leprosy but still needed health workers to take care of them.

Because many buildings/houses in colonies/leprosaria were built in the 1950's, most of them were in danger of collapse. About 4% of buildings were made of straw, and 48% were made of mud mixed with bricks. There were 45,869 square metres of buildings/houses in danger of collapse, which accounted for 47.56% of all buildings. Based on the survey, among all people affected by leprosy in colonies/leprosaria, 12,000 were living in houses in danger of collapse.

PEOPLE AFFECTED BY LEPROSY HOPING TO IMPROVE THE QUALITY OF LIFE

People who lived in the colonies/leprosaria were neglected, and the budget for their care was less than 1 US dollar per day. In our many visits to these colonies/leprosaria we found that most people affected by leprosy were willing to leave them only if the government could provide the funds necessary for their daily needs and new leprosaria with good access for transportation and good health care.

Discussion

With the reduced leprosy prevalence and resources for leprosy colonies/leprosaria, their role the Leprosy Control Programme weakened in China. The majority of leprosy colonies/leprosaria had ceased to provide medical services for patients with serious leprosy

Table 4. Totals of all residents in leprosy colonies /leprosaria at all levels in 2004 in PR China, by Province*

Provinces	No. of patients and ex-patients living in leprosy colonies and leprosaria	No. of patients and ex-patients with grade 2 disability(%)	No. of patients and ex-patients needing attendance(%)	Number of patients' and ex-patients' healthy offspring	No. of patients' and ex-patients' healthy spouse or relatives
Fujian	441	329 (74.6)	244 (55.3)	29	35
Hebei	49	43 (87.8)	16 (32.7)	0	0
Liaoning	75	65 (86.7)	21 (28.0)	0	0
Jilin	41	39 (95.1)	10 (24.4)	0	0
Shanghai	98	80 (81.6)	35 (35.7)	0	0
Jiangsu	1848	1686 (91.2)	1004 (54.3)	52	42
Zhejiang	492	428 (87.0)	139 (28.3)	0	0
Anhui	545	454 (83.3)	108 (19.8)	28	16
Jiangxi	956	910 (95.2)	357 (37.3)	68	32
Shandong	588	425 (72.3)	403 (68.5)	6	19
Henan	28	20 (71.4)	10 (35.7)	51	32
Hubei	679	396 (58.3)	207 (30.5)	63	38
Hunan	576	346 (60.1)	229 (39.8)	39	89
Guangdong	3483	2713 (77.9)	895 (25.7)	167	69
Guangxi	721	597 (82.8)	178 (24.7)	21	41
Hainan	966	310 (32.1)	202 (20.9)	0	0
Chongqing	131	97 (74.0)	50 (38.2)	19	21
Sichuan	2068	1232 (59.6)	744 (36.0)	1250	1049
Guizhou	1519	923 (60.8)	259 (17.1)	405	289
Tibet	31	29 (93.5)	8 (25.8)	0	0
Shaanxi	651	486 (74.7)	231 (35.5)	6	0
Gansu	103	81 (78.6)	44 (42.7)	9	0
Qinghai	61	36 (59.0)	36 (59.0)	17	7
Xinjiang	36	25 (69.4)	10 (27.8)	27	15
Yunnan	2567	1680 (65.4)	952 (37.1)	1044	277
Total	26178	13430 (51.3)	6392 (24.4)	3301	2071

*Provinces without patients and ex-patients living in leprosy colonies/leprosaria were not included.

reaction and other complications, and were acting only as collecting house for old burnt-out cases.

The running of colonies/leprosaria in some Provinces and Districts was not cost-effective. Based on the survey, 18 Provincial leprosaria and 58 District leprosaria contained 99.5 and 46.3 old people affected by leprosy, respectively. However, there were 61.9 and 30.9 staff working there, respectively. Although some leprosaria still admitted new patients, there were only 255 patients hospitalised for treatment among 76 leprosaria.

The quality of health care in leprosy colonies/leprosaria was neglected. Because most leprosy colonies were located in remote places where transportation was very difficult, each leprosy colony only had 5.3 staff, treated less than one active patient and took care of 26.4 old people affected by leprosy, on average. With the decreased level of health workers and shortage of medical materials, many people affected by leprosy lived with serious sole ulcers and eye problems and lacked necessary dressings and drugs. This condition mainly occurred in colonies.

What should be the role of leprosy colonies/leprosaria in the present leprosy control program in China?

What should we do to improve the quality of life and care for people affected by leprosy living in colonies/leprosaria? China was eager to learn the successful experiences from other countries in solving the problems of leprosy colonies/leprosaria. There were not many articles addressing the problems of leprosy colonies/leprosaria in recent years, although many countries had faced a lot of similar problems due to reduced resources and the number of new patients. In the global strategy for further reducing the leprosy burden and sustaining leprosy control activities (2006–2010),¹ the role and the situation of leprosy colonies/leprosaria was not mentioned. There seemed no definitive answer about our question. Brazil had paid attention to former Hansen's Disease colonies and made it a target of public policy to improve the quality of residents' life.² In our country, there was one author who studied the role of leprosy villages and leprosaria in Shandong Province³ and the situation of the social, economic and medical needs of people affected by leprosy in leprosy villages in Shandong province.⁴ Neglecting leprosy colonies/leprosaria seemed to be a common phenomenon in some countries in the late phase of leprosy control.

Based on the actual situation of leprosy colonies/leprosaria in China, the following policies and strategies are recommended for solving their problems:

1. Leprosy colonies/leprosaria located in remote and isolated places should be closed. NGOs and local governments should be discouraged from reconstructing them. Although reconstruction might improve the quality of life and care it would neither solve the long-term problems nor reduce stigma towards leprosy and would waste resources.
2. Considering that stigma towards leprosy still exists in some areas in China, and that the provision of medical services for leprosy patients by general hospitals in China was not widely acceptable to hospital managers, doctors and the healthy population, special hospitals for people affected by leprosy at Provincial or National level should be established, in the same way as special hospitals are set up in China for patients with Tuberculosis, AIDS, Hepatitis and mental disease. This policy also proved successful in Japan in former times;⁵ the life and care quality of people affected by leprosy having been guaranteed in the National leprosaria in Japan. However, the tragic consequences of

compulsory isolation of patients should not be repeated. The human rights of patients and people affected by leprosy should be fully respected. New leprosaria at District, Provincial or National level should be established in beautiful places near the city and with transportation. Some existing leprosaria with good transportation and facilities could be chosen for reconstruction as new District, Provincial or National leprosaria. All patients and people affected by leprosy from closed colonies/leprosaria would be moved to the newly established or reconstructed leprosaria.

3. Those old leprosy colonies with good natural resources but with predominantly healthy populations could be transformed to natural villages under the support of local governments and NGOs. Building roads, repairing houses, supplying tap water and electricity, and building schools in these colonies/leprosaria by local government and NGOs would be encouraged. Old people affected by leprosy could choose to transfer to newly established leprosaria or to remain where they were.
4. Local government should arrange an adequate number of health care workers to work at the newly established or reconstructed leprosaria. The government should also provide the necessary funds for these newly established or reconstructed leprosaria, for the basic living costs and medical services for patients and people affected by leprosy. The leprosaria should be open to people affected by leprosy with serious complications caused by leprosy who were previously living outside leprosy colonies/leprosaria.
5. The human rights of all patients and people affected by leprosy should be fully respected. They would not be forced to transfer to newly established or reconstructed leprosaria, and if they moved into the new or reconstructed leprosaria and felt them to be unsatisfactory, they would be free to leave.
6. The newly established or reconstructed leprosaria should have the following functions:
 - a. The provision of general medical services for patients and people affected by leprosy as required.
 - b. Providing physical, psychological and social rehabilitation for the patients and people affected by leprosy to improve their quality of life.
 - c. Functioning as the Reference Centre: the routine tasks for reference would be to diagnose doubtful patients with leprosy, to deal with leprosy reactions, eye problems, side-effects caused by anti-leprosy drugs and other complications related to leprosy.
 - d. Leprosaria, when having very few patients and people affected by leprosy, should have the ability to transform into hospitals for chronic diseases, occupational diseases or sanatoria to avoid wasting this valuable resource.

Although leprosy is not a big burden at present, the impact of the disease is profound due to its medical and social characteristics. Building a harmonious society needs to respect the basic human right of all people affected by leprosy including their dignity; the right to a better life and the right to basic medical services. It is helpful that China's Central Government has understood the situation of leprosy colonies/leprosaria and will allocate a great sum of funds to improve the situation of leprosy colonies/leprosaria. We hope that the problems of colonies/leprosaria in China will be solved satisfactorily in the near future.

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