Government health workers as implementers of prevention of disability measures: an assessment of a prevention of disability project in selected counties of Guizhou Province, Peoples’ Republic of China

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Summary
Objective The purpose of this study was to assess the effectiveness of government health workers as agents for the prevention of disability.

Design A prevention of disability (POD) project for people affected by leprosy was conducted in nine counties of Guizhou Province, Peoples’ Republic of China. The project was implemented by government health workers. In accordance with the principles and national criteria of the National Centre for Leprosy Control (NCLC) POD Pilot programme, 1215 people affected by leprosy were selected, followed up and assessed with the use of impairment summary forms through which essential indicators were routinely collected.

Results Most improvements of disabilities occurred in the 1st year of the POD project. Fifty five people with neuritis were detected and treated with prednisolone out of 262 new patients; 47 of these improved; 1130 people completed a 3-year self-care programme; 88.5% of red eyes, 83.9% of hand ulcers and 62.8% of simple foot ulcer cases healed during that period. One hundred and ninety six people who presented with complicated ulcers were treated; of these 73 (37.2%) people presented with feet free of ulcers at the end of the project period.

Conclusion The POD project was a cost-effective method of preventing further disability occurrence among people affected by leprosy. Government health workers were generally able to implement and monitor the project effectively. Most of people affected by leprosy were satisfied that the improvements in their disabilities had been due to self-care. The programme had helped them to increase their confidence to implement self-care activities.
Introduction

Leprosy is a major cause of preventable disability: i.e. impairments, problems related to activities of daily life and social exclusion resulting from stigma.\textsuperscript{1–3} Twenty years ago the major leprosy control strategy was the implementation of MDT. Guidelines on leprosy control contained very little on the prevention of disability except for the disability assessment methods (WHO 1988a).\textsuperscript{4} The Global Strategy for further reducing the leprosy burden and sustaining leprosy control activities (2006–2010) has been widely welcomed and endorsed. The guidelines suggest a greater emphasis on the assessment of disability at diagnosis, so that those at particular risk can be recognised and managed appropriately. Prevention of disability (POD) is also described in some detail as there is a need for much greater coverage with basic POD activities.\textsuperscript{5} This is an important component of ‘quality leprosy services’ emphasised in WHO’s Global Strategy.

Guizhou province is a mountainous area located in southwest of China with a population of 39,058,858 in 88 counties. It covers a total 171,000 km\textsuperscript{2}. 37.8\% of the population are ethnic minority groups and 85.5\% of the whole population are farmers or agricultural workers. The average annual income for a farmer in 2006 was estimated to be about $250.00. Guizhou is one of the main leprosy endemic areas in China with every county in the province being affected. The 203 new cases detected in 2006 accounted for 15% of the total new cases found in China. About 200 new cases were detected annually over the past 5 years. The disability rate among these new cases was 23%.

Following a pilot POD project initiated and implemented by the NCLC Nanjing, a prevention of disability and rehabilitation programme was designed and implemented by the Guizhou Institute of Dermatology in partnership, first with The Leprosy Mission International and then with American Leprosy Missions. The plan was to implement a programme based on the same objectives of the NCLC POD Pilot programme. From 2000 to 2007 two 3-year POD and rehabilitation projects were implemented in nine pilot counties of Guizhou, China which were sponsored by American Leprosy Missions (ALM). A goal for implementing a POD and rehabilitation project in Guizhou was to explore the efficacy of approaches of implementing POD in the field. We also hoped to understand the efficacy and challenges of a POD and rehabilitation project as a method for improving disabilities and for preventing the worsening of disabilities. We were particularly interested to ascertain what would be the effects of early detection and treatment of neuritis by the health services. We were also interested to learn more about the impact that a POD and rehabilitation project would have on the lives of people affected by leprosy.

The Guizhou Institute of Dermatology is a department of the Provincial Communicable Disease Centre (CDC). It is responsible for the training, monitoring and supervision of the POD project in the pilot counties. The county level CDCs provided training, medical services and took responsibility for the follow-up of leprosy cases. All people were assessed using impairment summary forms designed by the NCLC. Assessments were conducted at the start of the programme, at follow-up dates and at the close of the programme according to the requirement in the National POD guidelines. At the end of the project, a final project evaluation for the pilot counties was completed by a team of domestic and foreign experts organised by ALM.
Method

SELECTION OF PROJECT COUNTIES

From two prefectures we selected the following counties: Xinyi, Puan, Anshun, Pingpa (Qianxinan Prefecture), Kaili, Danzhai, Jianhe, Liping and Majiang (Qiandongnan Prefecture) as project areas. Selection was based on the endemicity of leprosy and the availability of leprosy services in the health service system. The POD & rehabilitation project in Xinyin, Puan, Anshun and Pingpa Counties was implemented by independent skin disease prevention stations. These skin stations contributed a specialised leprosy component to the general health service and were responsible for providing leprosy-specific services. In Kaili, Danzhai, Jianhe, Liping and Majiang Counties the project was implemented by County level CDCs.

SELECTION OF CASES

A base-line survey was carried out before the POD project; 2786 people affected by leprosy in the pilot counties underwent a physical examination and disability assessment at the beginning of the POD project – 1215 cases, who presented with either WHO Grade I or 2 disabilities, were selected for the project.

MANAGEMENT OF THE POD PROJECT

A leadership was established for the POD project and separate offices were set up in the Provincial Institute of Dermatology and at the prefecture CDCs which had responsibility for the administration, training, and supervision of the field work at county level. The Provincial Institute of Dermatology distributed all required record forms and materials for smoothly implementing the POD programme in each county. Every six months, a report was prepared and sent to the National Center (Nanjing), ALM, and to the Provincial Bureau of Health.

Seventy-two public health workers from nine pilot counties attended POD training before the project was launched. The training was facilitated by experts from the NCLC Nanjing and the Guizhou Institute of Dermatology.

Skin Disease Prevention Station Service System (vertical health service)

There were skin disease prevention stations in Xinyin, Puan, Anshun and Pingpa Counties. These provided a specialised service for the people affected by leprosy; leprosy was given priority status in skin disease prevention stations. The public health workers from the stations took responsibility for training and follow-up of cases. In accordance with the requirement in the National POD guidelines, health workers examined indicators over the project period to ascertain changes in impairment. All changes were recorded and reported to the Provincial Institute of Dermatology on prescribed dates.

County CDC

County CDCs in Kaili, Danzhai, Jianhe, Liping and Majiang Counties were responsible for integrating leprosy services into general health service at town and village levels.
The public health workers in the county CDC had combined POD work with TB control or vaccination activities in their routine work. It became normal practice for health workers to monitor and follow up POD activities while conducting other work simultaneously. For new leprosy patients, the staff from the CDC distributed Multi-Drug Therapy (MDT) and monitored patients’ POD activities according to the National POD guidelines. The CDC also assumed responsibility for the training of health workers in the general hospitals and clinics at town and village level. After training, responsibility for further medical service provision and for the POD follow-up for people affected by leprosy was then delegated to town and village health workers. This was particularly essential to reach the most remote towns and villages.

Results

POPULATION CHARACTERISTICS

During the baseline surveys conducted in the nine pilot counties, 2786 people affected by leprosy were checked by public health workers; 1215 cases were selected to participate in the POD project. The sample comprised 866 people from leprosy villages and 349 people living in general communities – 747 subjects were male and 468 subjects were female – 351 subjects were aged greater than 60 (864 subjects were aged less than 60). During the project, 85 cases either died or were lost to follow-up. 1130 cases completed the 3-year POD project and were available for the final assessment at the close of the project.

SELF-CARE OF EYES, HANDS AND FEET

A 3-year programme of self-care was instituted for 1130 cases; 88.5% of all red eyes, 83.9% of hand ulcers and 62.8% of foot simple ulcers healed completely. There was no significant change in the number of people with vision impairment. Please refer to Figure 1.

Figure 1. Changes in impairments in POD program area over 3 years.
COMPREHENSIVE THERAPY FOR COMPLICATED ULCERS

People with complicated ulcers were offered comprehensive therapy; this included minor surgery, rest, dressing, protective footwear or modified insoles. There were 196 people who presented with complicated ulcers. They were followed up during the 3-year programme and the changes recorded are shown on Figure 2.

EARLY DETECTION AND TREATMENT OF NERVE FUNCTION IMPAIRMENT

During the POD project, 262 active and new cases were followed up regularly with standardised nerve function assessment to detect nerve function impairments so that they might be treated early. New patients were monitored once a month for a period of 6 months after they were diagnosed. When nerve function impairment (NFI) was found to have been evident for 6 months or less, it was considered to be ‘recent’ and patients were treated with prednisolone. During the project, 55 out of 262 people were diagnosed as presenting with frank or silent neuritis; 87.3% of cases occurred during MDT and 12.7% after release from treatment (24 months for MB cases is standard policy in the Peoples Republic of China). There were 18 cases (32.7%) of silent neuritis among all patients with neuritis. The data relating to patients with neuritis are shown in Table 1.

Discussion

A total of 1215 people affected by leprosy participated in the prevention of disability and rehabilitation programme. All cases were regularly assessed and changes in disability status during the project period were recorded. Eighty five cases were lost to follow up or died during the 3-year project accounting for 7% of all cases. At the end of the project, 1130 cases had completed the 3-year programme. Final project evaluations were carried out by experts from ALM, NCLC and Guizhou Provincial Institute of Dermatology in the counties where the projects had been conducted.
Two hundred and sixty two (MB 211, PB 51) active and new cases were regularly followed up by public health workers who applied nerve function assessments for the early detection of NFI. During this project, 55 out of 262 cases (incidence rate of NFI was 21%) were diagnosed as presenting with neuritis, of which 32.7% were silent. The silent patients with neuritis accounted for 6.9% of all observed cases; 87.3% of NFI cases occurred during MDT and 12.7% occurred after people were released from MDT. There are various results reported from the field that can be used for comparison. Jiang reported an incidence rate of NFI 13.6% of which 62.6% were silent neuritis. According to annual reports prior to the POD project, the NFI incidence rate was less than 10% for new leprosy cases and no patients with neuritis were ever reported by public health workers. Therefore, we suggest that the POD methodology presented an effective approach for the early detection of NFI in the field and suggest that it should become standard practice to reduce any further increase in disability among new cases.

The regular monitoring of nerve function should be a routine component of leprosy control work, however it should be noted that the public health workers reported that it was very difficult for them to detect early nerve function impairment in the patients with neuritis (ball pen method was used). We also found that some public health workers were not able to determine the appropriate dosage of prednisolone when they were faced with complex situations (e.g. only standard tapering doses† were given even when NFI was found to be getting worse). More appropriate guidelines for the management of neuritis by health workers need to be established.

During the project period, most of the patients benefited through improvements of their disabilities. The self-care programme was particularly useful for addressing cases with hand and foot crack cases (these were reduced by more than 95%). The result was similar to that reported by Zhang et al. Healed cracks were the first sign that people could observe and appreciate as an indication of improvement of disability that they had achieved themselves through doing frequent self-care. These changes were normally reported at 3rd month to 6th month by patients. When people observed the changes, they began to believe that the self-care activity was an effective method to make them better. Significant improvement to simple ulcers on hands and on feet was also noted. Most people reported notable changes or healing after 6th month of applying self-care (free footwear was provided to people conducting self-care who had foot ulcers). There was good acceptability of the footwear provided because people reported that it was suitable for them to do farm work. It was also found that people

<table>
<thead>
<tr>
<th>Type</th>
<th>Observed cases</th>
<th>During MDT</th>
<th>After MDT</th>
<th>Frank Neuritis</th>
<th>Silent Neuritis</th>
<th>Total</th>
</tr>
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<tr>
<td>MB</td>
<td>211</td>
<td>32</td>
<td>6</td>
<td>26</td>
<td>12</td>
<td>38</td>
</tr>
<tr>
<td>PB</td>
<td>51</td>
<td>16</td>
<td>1</td>
<td>11</td>
<td>6</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>262</td>
<td>48</td>
<td>7</td>
<td>37</td>
<td>18</td>
<td>55</td>
</tr>
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55 cases were treated with prednisolone, following the national fixed regimen: 47 improved and 8 cases did not change.

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†The regimen used for MB cases was a 24 week tapering course of prednisolone, starting at 40mg daily. PB cases were given a 12 week tapering course with the same starting dosage.
associated the footwear with the healing of ulcers. Healed ulcers appeared to have been the most important factor in increasing peoples’ confidence that simple, self-applied methods could address their impairment problems. We found that the first year of the POD project was a very important period because it was during this time that peoples’ determination to adopt self-care behaviour was decided. Self-efficacy had been a gradual but positive development which motivated individuals to change their behaviours. The practice of self-care became a part of the daily activities of people affected by leprosy and we suggest that it was primarily self-care which explains the improvement in the disability profile during the POD project.

It was noted that for either simple or complicated ulcer cases, the reduction in ulcers in the 1st year of POD project was higher than it was in the 2nd or 3rd year. We also noted that certain factors appeared to have a negative influence on peoples’ behaviour which resulted in a decrease in their effort. Environmental factors appear to have been significant; for example, most people were rural agricultural workers and as such they were compelled to undertake hard, laborious work. Such work was disadvantageous to disability control and also gave little time for resting ulcers or wounds.

Some people also needed to overcome actual or anticipated discrimination in their communities during the period of learning and undertaking self-care. It had been noted that some people had reported loss of respect from their families when it was apparent that the impairments they had were due to leprosy, others were denied normal familial interactions. In some villages, any activity or behaviour that marked individuals as different (e.g. wearing sunglasses) drew queries and demands for explanation. In some situations, when it was explained that different behaviour was a response to leprosy-related disabilities there had been adverse reactions (e.g. marriage offers from affected families were declined). It was doubtless that in some situations the threat of exclusion was perceived rather than applied because it was our experience that in many situations the general public did not exhibit negative attitudes towards people affected by leprosy.

Another serious weakness in our project was the low confidence and limited professional skills of public health workers to deal with difficult disabilities, especially complicated ulcers. When presented as a new project, all public health workers learned, practiced and taught people concurrently. Limited experience restrained public health workers from applying new methods. After we integrated the POD programme with town and village level general health system, this shortcoming became even more apparent. Some methods, such as plaster casting and splinting, could not be offered to subjects living in the general community because they were compelled to work everyday.

Evidence presented elsewhere (Li et al. Leprosy Review Vol. 79 No. 1, March 2008) also suggests that the influence of family members should be maximised in future projects. The Transtheoretical Model (TTM) explains how ‘helping relationships’ are an essential factor influencing behavioural change. ‘Helping relationships’, with attributes of caring, trust, openness and acceptance, are theoretically a catalyst that bring about positive changes in health behaviour. Limited helping relationships were likely to have been established with public health workers, but supportive family members were likely to have been a more significant influence that facilitated the positive health behavioural changes documented.

Although supportive health education for patients’ family members had been requested, family members were not given opportunities to attend workshops that may have enhanced their capacity to maximize support. Reliance solely on public health workers to transfer needed social skills was inappropriate because they too had been inadequately prepared to impart such knowledge. The extent to which family members were informed was actually
dependent on public health workers’ capability, sense of responsibility and their relationship with subjects during follow-up.

Anecdotal evidence was that where there were generally good relationships and a basic but adequate understanding of leprosy and self-care skills, people readily embraced self-care behaviour (family support was particularly essential for people with severe disabilities). However, where it had been noted that people preferred to hide their impairments for fear of discrimination, the POD project caused distress with family members becoming antagonistic to the project.

Cross reported that socioeconomic rehabilitation can play a major role in improving quality of life by enhancing social integration and may even reduce leprosy-related stigma. It may be that a socio-economic component should be integral to a POD project to overcome some of the environmental issues observed by us. Such a programme may not only address the issue of privation, but may also be advantageous for the raising of individuals’ confidence and stature in their families which may enhance their opportunities to conduct self-care activities.

The POD project not only benefited people affected by leprosy, but it also promoted the cause of leprosy prevention and control in the pilot counties. Due to the POD project, local governments recognised that leprosy was still a health issue. Most local governments matched the funds given for the POD and rehabilitation project in the pilot counties. These were used to enhance standards of living for people affected by leprosy and their families (e.g., building new houses and increased subsidies).

In Guizhou, the POD project was advantageous for people affected by leprosy as it contributed either to the prevention of worsening of disabilities, or to preventing the worsening of established disabilities for people living in very difficult circumstances. We conclude that Government health workers can be effective agents of POD for people affected by leprosy. The programme should be replicated in all the counties of Guizhou.

References