Sustainable leprosy related disability care within integrated general health services: findings from Salem District, India

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Accepted for publication 7 September 2007

Summary  The main focus of leprosy control has been case detection and treatment delivery with relative neglect of prevention of disability. Absence of reliable data and lack of research have added to the problem. This raised concerns about the capacity of the general health system to address the needs of people living with leprosy-related disabilities.

In this prospective study appropriate services for people living with leprosy-related disabilities were introduced in the form of self-care training, guidance and monitoring by the general health staff facilitated by a non-governmental organisation leprosy centre in a district in south India with a population of 3·1 million (estimated in 2005).

The staff identified 1232 people with leprosy-related disabilities and trained them in self-care. Follow-up assessments indicated that 86% were found to be practising self-care regularly and all the 239 general health workers were found to be actively involved. The most heartening outcome was the healing of plantar ulcers in 70% of people at the 1-year follow up. This intervention is sustainable because of the simplicity of the procedures and the involvement of all health staff including supervisors.

Introduction

Multi Drug Therapy (MDT) has been successfully implemented in India since 1984, under the National Leprosy Eradication Programme (NLEP), with participation from a large number of Non-Governmental Organisations (NGO). Leprosy control was integrated in Tamil Nadu state in 1997 followed by other states in India. MDT services are now provided by the general health system in all states. Care of disability has been one of the neglected components of the
programme right from the initiation of NLEP in 1983, even more so now, after integration. Even though the programme tried to introduce Prevention of Disability (POD) services in 1997 through an approach involving the training of a limited number of workers along with a few patients in POD camps in Primary Health Centres, it lacked intensity of purpose and remained a stand-alone intervention with no follow-up. No attempt was made to update the baseline data on people living with leprosy-related disabilities. Information on the magnitude of the problem was not available, and therefore it was difficult to motivate workers to retain interest in the activity. POD services were provided only by NGO centres.

Disability prevention and management through cost-effective methods are the priority after MDT and case detection. The POD technology available today is limited and too complex and needs to be improved and simplified for application in the field.4,16

The research question is: can POD services be implemented in a district through the integrated set-up with facilitation by an NGO? The ultimate aim is to enable the Government to establish sustainable POD care services in a large area. The NGO project which has long-standing experience in implementing leprosy control activities including provision of appropriate services to those affected with disabilities will play the enabler role: identifying along with the district programme officer a core team for planning and implementing POD in the district, and guiding the team for capacity building of peripheral staff in the Government health system to help people living with disabilities take care of themselves. Over a period of 2 to 3 years NGO involvement will be tapered so that its role will be only in attending review meetings and occasional visits to the field with the core team.

Methods

Salem was chosen because of the presence of a NGO leprosy centre and a large number of leprosy cases with disabilities reported from the district in the last 20 years (more than 1500 cases). Salem District has a population of 3,123,535 (estimated in 2005) with 20 revenue divisions and 70 PHCs/Urban Health Centre each covering about 30,000 people. Every division (population 100,000) has an in-patient facility in one of the PHCs. Each PHC, which is headed by a Medical Officer and assisted by a Supervisor, has 5 to 6 sub-centres each covering a population of 5,000 with a female health worker called a Village Health Nurse (VHN) and a male worker called a Health Inspector. Urban areas are divided into smaller administrative division units called wards. There are 1,232 people with grade 1 and grade 2 disabilities and a new case detection rate of 0.93 per 10,000, 3.1% (Apr 2005–Mar 2006) of whom have a deformity. Salem, like other districts in Tamil Nadu, has a large number of ‘unipurpose’ staff from the leprosy control programme, and their involvement in leprosy control is confined to health education and treatment delivery to leprosy patients registered at the PHCs. Their presence in large numbers (105 Leprosy Inspectors, 20 Non-Medical Supervisors) also deters general health workers from participating in leprosy control. The District Leprosy Officer (DLO), along with a Non-Medical Supervisor, coordinates leprosy control in the district.

St. Mary’s Leprosy Centre had been implementing leprosy control activities in Salem urban district (population 300,000) since 1960. The MDT programme was started in 1986. When the vertical system for NLEP was integrated in 1997 the programme activities were taken over by the general health service. NGO centres were requested by the Government (1998) to provide essential support in establishing MDT services in urban areas where the programme was either non-existent or inadequate. Accordingly, St. Mary’s Leprosy Centre
assisted 21 urban health centres in Salem City in establishing MDT services including care of
the disabled. Impressed by the result, the District Leprosy Officer (designated as Deputy
Director of Medical Services – Lep) decided to extend the POD service to the whole district.
Support for POD in the district is provided by St Mary’s Leprosy Centre through its Medical
Officer and Physiotherapy Technician. The POD camp approach as per NLEP guidelines was
started in late 2002 when a limited number of people with leprosy-related disabilities and a
few PHC staff were given a 1-day training course with assistance from the NGO centre. It was
observed that the impact of this training in terms of people practicing self-care and
supervision of them by PHC staff was unsatisfactory. This led to a revision of the strategy.

MODIFIED STRATEGY

The District Leprosy Officer conducted a series of meetings with the chief of public health
programmes in the district (Deputy Director of Health Services), the municipal
administration and the NGO. A plan was worked out based on the POD camp methodology
introduced earlier by the Government of India with modifications. It was decided that the
Government general health staff would implement POD services with technical support from
the NGO project which trained a core team of trainers from the Government consisting of the
DLO and a Non-Medical Supervisor. Training schedules and checklists were prepared
(March 2004). Initially PHCs with large numbers of cases with disabilities were selected. In
the monthly meetings at selected PHCs the general health staff were briefed about the
programme; the sub-centre and village-wise lists of people living with leprosy-related
disabilities collected by the Leprosy Inspectors from existing records were handed over to the
health workers with a request to contact the patients and mobilise them along with family
members (at least one for each patient or neighbour if there is no other member in the family)
to a named PHC on the next meeting day, for training. They were also asked to update the list
(patient dead/migrated). Hands-on training was given to all staff including the Leprosy
Inspectors and Supervisors in the PHC with a demonstration in self-care. Training was
arranged in these POD camps for 2 days (the first day on theory and the second day on
practical demonstrations with patients). Workers were asked to visit patients regularly
(whenever they visited the villages for their routine work which was twice a month). They
ensured the involvement of the person in his/her own self-care by his/her knowledge of the
procedures and the availability of the tools for self-care, in their homes. They recorded
the findings in a personal record after each visit (Figure 1).

Immediately following the training in the POD camp, the core team members
accompanied health workers in the field to give further training in monitoring the patients.
They later visited the PHCs as per the schedule and interacted with the staff. Patients with
serious problems were visited by the core team member along with a health worker for
assistance. One small pocket notebook was given to each person with baseline details. Any
person from the health services visiting the patient entered his/her remarks. NLEP staff in the
PHC provided support to health workers with guidance, supervisory visits and by counselling
patients.

Self-care procedures: Self-care procedures were based on Inspection, Soaking, Scraping,
Oiling and Dressing (ISSOD).

a. Inspection: Daily inspection of hands and feet to identify signs of damage (redness,
       injury, fissures).
b. Soaking: in plain water for about 30 minutes. Use of any vessel available at home including broken mud pots.

c. Scraping: Use of a stone having a rough surface without sharp edges. It should fit into the hand for good grip (not large or too small). Scraping to be done only after adequate soaking. Scraping should be gentle over callosities/fissures.

d. Oiling: Neem oil is applied immediately after soaking when the skin is still moist. Neem oil is readily available in this region. This bitter tasting oil with a pungent smell deters insects and rodents.
e. **Dressing (for people with ulcers):** Use of strips of old clean cloth available at home. These strips of cloth should be washed and dried in the sun before using as a dressing for an ulcer.

None of the materials needed for ISSOD were supplied from the health service. Materials available at home were used.

This POD programme was implemented in four urban divisions and five rural divisions initially during 2004 and extended to four more rural divisions in 2005. The NMS and Physiotherapy Technician visited clients at least twice a year and assessed their progress using a checklist (Figure 2). The outcome in terms of knowledge and practice of self-care and supervision by the health workers were recorded.

## Results

The district recorded 1,232 people cured of leprosy but with a disability in nine rural divisions and four urban divisions (population about 1.9 million) after verification through field visits.

<table>
<thead>
<tr>
<th>1. Interview of person living with leprosy-related disability (PLWLD)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Visit of VHN to patient’s house</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>ii. Implements of self-care available (container, stone, clean cloth)</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>iii. Skin of sole/ palm, soft &amp; supple</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>iv. Existing calllosities show signs of decrease / thinning</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>v. Deformities of hands /feet – mobile</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>vi. Edges of ulcers sloping &amp; show signs of healing</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>vii. Footwear (MCR or appropriate) show signs of usage</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>viii. Knows exercises for hands /feet / eyes (strike off if not applicable)</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Interview of VHNs</th>
<th>VIHN 1</th>
<th>VIHN 2</th>
<th>VIHN 3</th>
<th>VIHN 4</th>
<th>VIHN 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub centre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Has visited houses of PLWLD</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>ii. Has the list of PLWLD</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>iii. Knows the steps of SSOD</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>iv. Knows the steps of exercises of hands /feet / eyes</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
<tr>
<td>v. Has referred PLWLD to PHC for complications</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
</tr>
</tbody>
</table>

Figure 2. Checklist for supervision of POD.
This included 631 people identified by health workers whose names were not on the register. Grade-I disability was present in 200 (16.2%) and Grade-II in 1,032 (83.8%) people. The prevalence of people with leprosy-related visible deformities in the community was 6.2 per 10,000 in the divisions covered by POD programme in the district.

The District team trained 1,643 general health staff. On an average each VHN had four to five people with leprosy-related disabilities. Most people (86.2% – both rural and urban areas) reviewed in the self-care programme were practicing self-care (Table 1).

Initially ulcers were present in 516 (41.8%) of people with leprosy-related disabilities. Ulcers healed in 364 people (70.5%). The number of people practising self-care was similar in urban and rural areas. The success rate for healing of ulcers was higher ($P < 0.0001$) in urban than in rural settings. Eight hundred and forty seven people were provided with MCR footwear; 81% of the footwear was provided from funds generated from the community by the health workers. Towards the end of the year the involvement of the NGO became less intense giving an opportunity for government staff to own the project totally so that it would become sustainable. The district team reduced the frequency of visits to the PHC. NLEP staff and supervisory staff at PHCs took an active part in supervising the self-care programme. Medical Officers in PHCs reviewed progress during routine monthly meetings with field staff.

**Discussion**

Annually about 2% (about 12,000) newly-detected leprosy cases in India have visible deformities adding to the large number living with disabilities. Few attempts have been made to assess the magnitude of the problem of disabilities because of the operational difficulties involved. Even the validation studies carried out in the recent past have failed to shed light on this important aspect of the leprosy problem. Those living with disabilities are left to fend for themselves. The POD programme supplies footwear to a limited number of people with leprosy-related disabilities, and reconstructive surgery for a few in need. Social and operational factors affect the development of a strategy for the care of the disabled which should be specific and designed to meet local needs and situations (WHO Global strategy 2006–2010). Care of the disabled is labour-intensive and requires motivation and

**Table 1. Results of self-care programme in areas covered in Salem District (2005 to 2006)**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Urban (%)</th>
<th>Rural (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade I disability</td>
<td>72 (20.9)</td>
<td>128 (14.4)</td>
<td>200 (16.2)</td>
</tr>
<tr>
<td>Grade II disability</td>
<td>273 (79.1)</td>
<td>759 (85.6)</td>
<td>1,032 (83.8)</td>
</tr>
<tr>
<td>Total Patients</td>
<td>345 (100)</td>
<td>887 (100)</td>
<td>1,232 (100)</td>
</tr>
<tr>
<td>Population</td>
<td>851,675</td>
<td>1,112,735</td>
<td>1,964,410</td>
</tr>
<tr>
<td>Prevalence of people with leprosy related disabilities</td>
<td>4 per 10,000 population</td>
<td>7.9 per 10,000 population</td>
<td>6.2 per 10,000 population</td>
</tr>
<tr>
<td>People with ulcers</td>
<td>129 (37.4)</td>
<td>387 (43.6)</td>
<td>516 (41.8)</td>
</tr>
<tr>
<td>Ulcer healed after SSOD</td>
<td>108 (83.7)</td>
<td>256 (66.1)</td>
<td>364 (70.5)</td>
</tr>
<tr>
<td>People practising self-care</td>
<td>329 (95.4)</td>
<td>734 (82.7)</td>
<td>1,063 (86.2)</td>
</tr>
<tr>
<td>People provided footwear</td>
<td>143 (41.4)</td>
<td>704 (79.4)</td>
<td>847 (68.7)</td>
</tr>
</tbody>
</table>

SSOD = Soaking Scraping Oiling Dressing.
commitment. It is often difficult to convince both those with leprosy-related disabilities and the health workers of the benefits of POD.

Several approaches\textsuperscript{1,2,5,7} to self-care programmes have been tried and all of them have reported a good success rate. The interventions reportedly involved NGO hospitals, unipurpose leprosy workers and/or community volunteers. These volunteers were mostly from leprosy-affected groups. The population covered was small, sometimes specific (leprosy colony) and the most important point of interest was the non-involvement of the general health system. Sustainability would be a serious problem unless general health service staff were involved in the programme.

There remains the need for a structured programme\textsuperscript{11} for empowering those affected and their family members in disability-prevention practices. Operational research is needed to improve coverage and access to basic POD measures.\textsuperscript{12} NGO projects are eminently suited to play the role of facilitators. In a programme where priority so far has been on providing basic services like case-detection and treatment, it is too much to expect that attention be given to the people with leprosy-related disabilities. Fortunately, there has been a change in the perception and the Government has recognised the need to provide support and guidance\textsuperscript{3} to people with leprosy-related disabilities.

POD was not a priority even under vertical programmes, but with integration patients will come closer to the service providers and there will certainly be pressure on the health service to treat a person holistically. A health worker may have at most two or three people with a disability to look after in a population of 5,000 or 1,000 families spread in few villages. The worker can visit these people at least twice a month during their visit to the villages for routine work. Their frequent visits bring them closer to the community which respects them for all their help. Appropriate training of staff, intense education of patients and family members with follow-up procedures\textsuperscript{6} can produce tangible results. In this study, 40% of ulcers healed within 12–24 weeks and another 20% healed within 48 weeks. Direct participation of health staff in self-care education of patients\textsuperscript{4} yielded positive results which were better in urban than in rural areas. This can be attributed to different lifestyles; in urban areas people do not travel long distances for their daily needs and better transport facilities are available. The provision of footwear was not adequate in NLEP. The NLEP budget which had provision for five pairs of footwear per month per district was the same for all districts irrespective of patient load and population. The general health staff along with the local NGO generated funds for footwear from the local community resulting in the issue of 847 pairs of footwear. The contribution of local donors was substantial, but local contributions for footwear cannot be sustained on a long-term basis and support from NGOs may not be available in all regions. Healing of ulcers ensures that people develop confidence in the health system.

One of the important requirements for effective intervention is the provision of transport support to the supervisor at the district level so that they can reach health workers and patients to identify problems and promptly institute remedial measures. No amount of motivated work can succeed unless workers are provided with adequate guidance and advice. The excellent guidance from the district leprosy team and support from district health authorities instilled confidence among health workers to take up the task. The availability of an effective referral system where all the stakeholders know what referral services are available adds to the strength of the programme. The concern shown by health workers as observed during supervisory visits and evaluation had a great influence in changing the behaviour of people with leprosy-related disabilities. Further, the use of materials available at home effectively
prevents dependency on the health services which enabled the practice of self-care regularly at home. This approach involves existing health care staff without the additional burden of records. They also witness the results first-hand and become convinced. Hence this is a sustainable process in implementing disability care. Success stories like the Salem project will certainly give impetus to the efforts and enough reason to make POD a priority component in leprosy control.

LIMITATIONS

- Local contributions for footwear cannot be sustained on a long-term basis.
- Support from an NGO may not be available in all regions.
- Availability of mobility of the leprosy team from the District leprosy office is a crucial factor.

Conclusion

Prevention of disability with the focus on educating patients to take care of their disabilities with guidance from their families/neighbours and health workers can be implemented in an integrated set-up. Good leadership, effective coordination, systematic field-based training and simplified operational procedures with back-up supervisory and referral support are necessary. Health workers are able to provide POD services to those in need and motivate them to take up responsibility for the care of their disabilities. This model can easily be adapted to different situations. There should, however, be clear guidelines for sustaining effective collaboration among all the stakeholders.

Acknowledgements

We thank all the general health staff for their wholehearted support, cooperation and involvement in POD care to leprosy-affected people in Salem District. We thank the state authorities and Salem city administration for their support. Dr. K. Soundrarajan, Deputy Director of Health Services, Salem District needs a special mention for his keen interest in the project. NLEP staff and staff of St Mary’s Leprosy Centre, Salem need a special mention for their active participation and support to general health staff. The services of Sr. Fransisca, Administrator and project holder of St Mary’s Leprosy Centre, Salem is highly appreciated for establishing good collaboration with the government system and guidance to staff. We thankfully acknowledge the services rendered by the leprosy centre in Chettipatti for the RCS done to the needy leprosy patients. We place on record the excellent tradition for patient-friendly services established by Government staff including the previous District Leprosy Officers in the district. We thank Mr. G. Kothandapani, Field Investigator, Damien Foundation India Trust for his assistance in compiling information and references.

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