Elimination of leprosy: the integration of leprosy related activities into the general health services of Tamil Nadu

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Introduction

Integration of the vertical programme into the general health services is an essential part of WHO strategy to eliminate leprosy.\(^1\) Integration is considered more cost-effective and feasible within national resources, thereby ensuring sustainability of leprosy services.\(^2\) Another attraction of offering leprosy services through the integrated set up is the anonymity enjoyed by patients in overcoming stigma in attending purely leprosy clinics. Thus, integration should significantly improve access and acceptability of the leprosy services. However, the success of integration can only be ensured when the general health services assume ownership of leprosy services and gain competence in diagnosis, treatment and management of leprosy complications.\(^3\) During an International Workshop organized by the ILEP in 1996,\(^4\) several guidelines were formulated for responding to change from vertical to integrated set up. This included a careful situational analysis on the magnitude of leprosy problem and assessment on whether leprosy control services can be adequately provided at all levels of the general health system at a minimum cost.

However, it may not always be possible, to make such a smooth transition, due to peculiar administrative or political considerations prevailing in certain areas. The situation in Tamil Nadu, India is one such, where it became imperative to integrate leprosy services into the general health service without adequate preparations in order to overcome possible pressures to resist change. In this paper the process of integration adopted in Tamil Nadu and its impact on case detections and elimination of leprosy are described and some recommendations made.

Background to integration in Tamil Nadu State

Following the introduction of the Multi Drug Therapy (MDT) programme, the prevalence of leprosy in Tamil Nadu in the MDT districts was reduced from 118/10,000 in 1983 to less than
10/10,000 in 1994. As early as 1991, an attempt at integration was made, but abandoned when it became evident that the programme staff was not in favour of the initiative. A cost analysis conducted by the Tamil Nadu State Department of Health concluded that the National Leprosy Eradication Programme (NLEP) was no longer cost-effective as a vertical programme. The efforts of the government to integrate leprosy services with Primary Health Care (PHC) services were renewed as a consequence of this finding. A committee headed by the Director of Medical and Rural Health Services of Tamil Nadu was formed in November 1996 to work out the details of integration. The committee consisted of various stakeholders, including representatives of the NLEP Staff Associations and the first author (P. S. S. Rao) as NGO Representative. Based on the committee’s recommendations, plans for integration were set in motion, which resulted in a government order for integration being issued in June 1997, despite opposition from the NLEP staff. In July 1997, Tamil Nadu became the first state in India where the vertical NLEP was integrated with the PHC system. The integration was effected without proper planned preparatory and transitional phases to overcome possible pressures to resist change.

The leprosy services were given only 1 month to wind-up and merge with the PHC services, which created many problems. The personnel were in a hurry to close their accounts and get their transfer orders. The Leprosy Control Unit (LCU) and peripheral centres had to be vacated at short notice, and hence some of the staff dumped the records, treatment cards and registers in the District Leprosy Office instead of these being handed over to the respective Primary Health Centres. This problem was further compounded by the lack of geographic matching between the Leprosy Control Unit (LCU) area and the corresponding PHC area. The PHCs did not have a list of patients currently on treatment in their area; on the other hand, the patients did not know which PHC they had to visit to continue their treatment. Most of the patients had not been told about integration and the transfer of their treatment to the PHC. Most were perplexed when the NLEP vehicle suddenly stopped visiting them, as they were not aware of the reason. In some districts, it took 2 months and in others as long as 6 months before these problems were sorted out. As the cards of some old RFT patients had not been transferred to the PHCs a few of the old treated patients were registered as new patients and started on treatment by the PHCs. Thus, there was confusion among staff as well as patients resulting in poor registration and treatment of new cases.

The leprosy workers were not trained to do public health work and the general workers to do leprosy work. The process of training commenced about 6 months after the integration and took approximately 1 year to complete. After integration, the male Multi Purpose Worker (MPW) attached to a Primary Health Centre was made responsible for new case detections. Each MPW is responsible for a population of 10,000 or 2000 families to detect suspects and is expected to be cover it in 10-15 days. All suspects are brought for confirmation to the PHC Medical Officer and Non Medical Supervisor each week. Patients are then followed up through the Primary Health Centre.

The Schieffelin Leprosy Research & Training Centre (SLR&TC) was established in 1955 in Gudiyatham Taluk of Vellore District, (formerly North Arcot District) in Tamil Nadu in South India. It began as a pioneering institution for development of reconstructive surgery, production of micro cellular rubber (MCR) footwear, provision of occupational therapy and health education. It quickly realized the need for a comprehensive leprosy control programme to diagnose and treat leprosy patients as early as possible. In 1962, it started general and special surveys registering and treating all leprosy patients in Gudiyatham Taluk (population at that time, 4,000,000 and currently 7,000,000). In 1968 the government of Tamil Nadu
entrusted the Taluk to SLR&TC as part of the National Leprosy Eradication Programme. Between 1968 and 1997 SLR&TC was responsible for treating over 25,000 leprosy affected persons in this Taluk. A computerized database was established on every new case detected and regularly updated during treatment. After the Government integrated the programme and took over the leprosy control activities, SLR&TC still continued to observe closely two of the four blocks in Gudiyatham Taluk as well in the Gudiyatham Town. It conducts a Skin Clinic in Gudiyatham Town, 5 days a week and in addition has three or four peripheral clinics primarily for follow up of new cases registered at base hospital or in the field clinics. It also continued to maintain the computerized database of all new cases that have voluntarily reported to SLR&TC and its peripheral clinics.

**Patients and methods**

The computerized data bank was used to select all new case detections during 1993–1996 (pre-integration) and during 1998–2001 (post-integration). The new case detected had all the basic demographic details including addresses and all pertinent history of leprosy, physical and laboratory findings. Only patients who were resident of the two blocks in Gudiyatham Taluk were considered. The mode of detection, whether voluntary reporting or through surveys were noted. The analysis was carried out through standard statistical packages for microcomputers. The differences in means and proportions were tested using the Normal curve. Student’s t-test was used for small samples. New case detections prior to and subsequent to integration included in this study are shown in Table 1.

A total of 349 patients reported voluntarily and 613 were detected through surveys during the 4-year period from 1993 to 1996 (pre-integration). During the 4 years after integration, i.e. from 1998 to 2001, 302 patients had voluntarily reported to our clinics and 33 detected through occasional surveys are considered.

**Findings**

The age and sex distributions of patients who reported prior to and after integration are given in Table 2.

Patients reporting voluntarily were of significantly higher age than those detected through

**Table 1. Patients reporting voluntarily or detected through surveys prior to and after integration in 1997**

<table>
<thead>
<tr>
<th>Period and sex</th>
<th>Voluntary</th>
<th>Survey</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-integration (1993–1996)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>349</td>
<td>613</td>
<td>962</td>
</tr>
<tr>
<td>Male</td>
<td>168</td>
<td>296</td>
<td>464</td>
</tr>
<tr>
<td>Female</td>
<td>181</td>
<td>317</td>
<td>498</td>
</tr>
<tr>
<td>All</td>
<td>302</td>
<td>33</td>
<td>335</td>
</tr>
<tr>
<td>Male</td>
<td>175</td>
<td>18</td>
<td>193</td>
</tr>
<tr>
<td>Female</td>
<td>127</td>
<td>15</td>
<td>142</td>
</tr>
</tbody>
</table>
surveys ($P < 0.001$). Further, after integration, patients reporting voluntarily were of significantly higher age, compared to those reporting before integration ($P < 0.001$).

In Table 3, the profile of patients detected prior to and after integration is shown.

Prior to integration, there was a slight male bias for those voluntarily reporting which increased further after integration. This is seen even among patients detected in surveys. As expected patients detected during surveys have a significantly higher child rate (persons less than 15 years), prior to and after integration. However, this proportion declined from 19% to 14% after integration among those voluntarily reported, though the difference was not statistically significant.

MB rate was significantly lower in persons detected through surveys (4%) as compared to those reporting voluntarily (16%), with no significant change before or after with integration. What seems to be more alarming is the significant increase of grade 2 deformity among those reporting voluntarily after integration, nearly double, when compared to the percentage prior to integration. This is true regardless of sex or age.

**Discussion**

Change is always fraught with difficulties but proper management strategies should be able to overcome these problems, including those related to attitudes and cooperation of staff.\textsuperscript{6,7} Sustainable leprosy services under the integrated set up should include at least passive case

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Pre-integration</th>
<th>Post-integration</th>
<th>Statistical significance</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Voluntary</td>
<td>Survey</td>
<td>Voluntary</td>
</tr>
<tr>
<td>Female rate</td>
<td>51.9</td>
<td>51.7</td>
<td>42.0</td>
</tr>
<tr>
<td>Child rate</td>
<td>18.6</td>
<td>40.5</td>
<td>13.9</td>
</tr>
<tr>
<td>MB rate</td>
<td>15.8</td>
<td>3.9</td>
<td>16.6</td>
</tr>
<tr>
<td>Deformity (grade 2 rate)</td>
<td>14.3</td>
<td>6.2</td>
<td>26.5</td>
</tr>
<tr>
<td>Male</td>
<td>18.2</td>
<td>10.2</td>
<td>28.0</td>
</tr>
<tr>
<td>Female</td>
<td>9.5</td>
<td>2.2</td>
<td>23.6</td>
</tr>
<tr>
<td>Adults</td>
<td>17.6</td>
<td>9.9</td>
<td>28.5</td>
</tr>
<tr>
<td>Children</td>
<td>0</td>
<td>0.8</td>
<td>11.9</td>
</tr>
</tbody>
</table>

*($P < 0.05$), **($P < 0.01$), NS = not significant.
finding, following of treatment and case holding, management of reactions and other common complications, care of patients with disabilities, training, supervision, drug supply and organization of a relevant leprosy information system. Unless the general health system is prepared to carry out these services, the patients’ welfare is likely to be jeopardized. The experiences in Tamil Nadu revealed the obstacles for successful leprosy elimination if not properly planned. An important element in success consists of training and motivating the general health staff to accept the new responsibilities. Although the Tamil Nadu government made tremendous efforts in this aspect immediately after integration, the impact of such training was lost due to prevailing commitments for other public health problems as well as the frequent turn over of staff.

An evaluation carried out by an independent agency (Community Health Department, Christian Medical College, Vellore) a year after integration showed a number of problems relating to performance of the leprosy programme and the lacunae in case detections, case holding and case management. All the paramedical workers were absorbed into general health system and given responsibility as a general health inspector. Despite the variation in their period of training or experience compared to their general health inspector, their wages were protected. Their skills were not uniformly used or passed it on to others. Much of the emphasis lay in detection of new cases and providing treatment with appropriate multi-drug therapy (MDT). The Government made tremendous efforts to overcome many of the lacunae but it would take a long time before all the workers are trained and equipped to handle their new responsibilities including prevention of impairments and disabilities and adequate rehabilitation.

There are deficiencies in efficient and appropriate coordination at the administration level in the district as well as in the supervision at the Primary Health Centre in case identification and treatment. Given the current level of Public Health in Tamil Nadu where the priorities still lie in reducing the high mortality and morbidity of infants and children due to gastrointestinal and respiratory disorders as well as continuing epidemics and the resurgence of tuberculosis, the priority for leprosy is lost. The general health system is yet to own the leprosy programme, and much needs to be done to bring the leprosy services to the level it was prior to integration.

There were no specific downward trends in case detections over the three years after integration; in fact, there are some slight increase. A Modified Leprosy Elimination Campaign I (MLEC I) was carried out prior to integration during February 1997 using an active case detection approach and 12,603 cases were newly detected.

Most of the investigators were the staff of the Primary Health Centres. A second MLEC was done in January 2000 based on passive case detection, and even so, nearly 12,000 new cases were detected. The third MLEC was done towards the end of 2001, and unofficial figures show more or less the same number.

Prior to integration, practically all patients were intensively followed up to complete their treatment schedule. After integration, the treatment completion rates were not monitored and seem to have reduced. The MLEC surveys indicated that a number of cases detected each year has remained static in spite of the passive method adopted during the second and third surveys. Had active search being done, the number of newly detected cases would have been much higher, as several patients still delay reporting early for treatment due to ignorance and stigma.

No public health problem can be solved satisfactorily without the active involvement of the communities served and a sensitiveness to the socio-psychological dimensions of the
disease and its treatment.\textsuperscript{9} Three thousand years of prejudice against leprosy superimposed by a lack of effective cure till recently cannot be ignored in any elimination strategy. While the availability of MDT has been a great boon, further progress is possible only by increasing Community awareness on free treatment facilities and availability of competent leprosy services at all primary health centers and medical centres.\textsuperscript{10} A health systems approach should be adopted to make the final push really effective in our efforts to eliminate leprosy. While integration is only a variation in the leprosy service delivery system, the other responsibilities of the State Government in terms of supervision, monitoring, drug logistics, referral services and periodic leprosy elimination campaigns remain. It will be over optimistic to assume that integration per se will eliminate leprosy. At best, it can provide an acceptable and accessible leprosy service; at worst, it can grossly underestimate the magnitude of the leprosy problem and result in complacency towards meeting the real needs of leprosy affected as seen in Tamil Nadu.\textsuperscript{11}

Poorly planned and fragmented surveillance systems and health objectives that are not explicit or highly politicized can only lead to wrong information,\textsuperscript{9} leading to a loss of all the advantages of a well organized National Leprosy Eradication Programme.\textsuperscript{6} In the recent evaluation on the progress made in eliminating leprosy from India, various States were classified into four groups: Tamil Nadu, Andhra Pradesh and Maharashtra are classified as group C category, contributing 22\% of the total leprosy cases all over India. It is stated that following their excellent achievement during the last 10–15 years these States still have prevalence of 3–4 per 10,000 population and face special problems of fatigue resulting from prolonged intensified activities, complacency resulting from past achievements, and ill-planned integration leading to loss of focus on leprosy elimination. These problems should be properly addressed so that they are able to attain their goal in time.\textsuperscript{8}

India is a vast country with diverse social, political, cultural, economic and organizational variables. Many states in India may be different from Tamil Nadu both in terms of health infrastructure as well as in attitudes of leprosy control staff. However, our experience should help other States to plan their strategies for integration carefully.\textsuperscript{1,12}

In summary, with significant declines in the prevalence of leprosy over the past 2 decades, integration of the vertical leprosy programme into the general health service becomes cost effective, acceptable and therefore an essential strategy to eliminate the disease. This change requires careful planning so that the general health system is capable of owning the new responsibilities. The vertical programme staff also need to be part of the change and motivated sufficiently in order to minimize any resistance to change. Tamil Nadu is the first in India to have integrated the vertical leprosy system. The transition was made without adequate preparations due to various political and administrative considerations. In this paper the background to such an integration and the repercussions which followed are described. MDT treatment was disrupted and patients were confused as to where they should report for follow-up. Training was too short term and its impact minimal. Job descriptions were not fully spelt out. The profile of patients detected before and after integration in Gudiyatham Taluk of Tamil Nadu confirms the lack of significant downward trends in leprosy and the possibility of several hidden cases. Further, the decrease in female and child rates and an increase in grade 2 deformity after integration causes alarm. Unplanned integration will require a much greater financial outlay and more hectic activities to overcome the problems that arise and if the interests of patients are to be protected. The experience of Tamil Nadu, both before and after integration, will help other states and countries planning integration to avoid such problems and help in making elimination of leprosy a success.
Acknowledgement

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References

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