CHAPTER VII

EPILOGUE

Leprosy is a devastating disease. It is devastating in the sense that the afflicted person has to live with a physically and mentally devasted life for the rest of his life. Though leprosy can be clinically diagnosed very easily, due to ignorance people allow it to grow to alarming proportions. The incidence of leprosy is very high in North Arcot District from which the researcher hails and hence he took interest in the study of this disease.

In the introductory chapter the need for and significance of the study is highlighted. To understand the various dimensions of the research problem, relevant literature is reviewed in the second chapter. The profile of leprosy at the International, National, State, District and Unit levels related to this study and Cost and Performance of NLEP have been brought out in the third chapter. Some of the medical aspects of leprosy, socio-economic and cultural aspects of the disease and also the legal aspects relating to the care and rehabilitation of the leprosy and the significance of health education in leprosy control from the points of view of (a) interrupting the transmission (b) diagnosis (c) treatment (d) preventing and controlling deformities and disabilities and (e) rehabilitation, have been brought out in the fourth chapter. In the fifth chapter the researcher has discussed the currently debated issue of integration of leprosy control work with PHC and has taken pains to analyse the pros and cons of the issue of merger.

Though the role of NLEP is praiseworthy it suffered certain drawbacks. Lack of proper planning, lack of motivation on the part of the leprosy workers, poor managerial monitoring, and use of infrastructure of NLEP for other purposes are a few of the ills that afflict the services of NLEP.
The investigator conducted an indepth interview of four hundred and fifty four leprosy patients who had completed the treatment belonging to eighteen villages in the eighteen subcentres of the Government Leprosy Control Unit in Tiruvettipuram in North Arcot District. The main findings of the study are as follows:

Majority of the respondents (69 percent) had poor housing conditions having overcrowding, poor ventilation, waste water stagnation by the side of the house, flies and mosquito problem, etc. Most of the respondents (67 percent) belong to nuclear family. 73 percent of the respondents have no or poor educational background. 49 percent of the respondents have no individual income and nearly half of the respondents' families belong to the low income group of Rs.501-1000 per month.

About 51 percent of the respondents did not know the cause for the disease they were suffering from. Nearly 98 percent of the respondents had delayed medical advice after the appearance of signs and symptoms of leprosy. Apart from making delay in diagnosis due to various reasons, large majority of the respondents had also made delay in taking allopathic medicine immediately after diagnosis. About 28 percent of the respondents used traditional medicine before taking allopathy.

Only 20 percent were regular in monotherapy whereas 87 percent were regular in MDT. Majority of the respondents (45.4 percent) revealed that prolonged treatment is the only reason for irregularity in taking treatment.

An overwhelming majority of respondents have benefited from the MDT within a very short period of treatment. There is no doubt that in terms of long-term benefits and cost- effectiveness, MDT, which is the only method
available for interrupting the transmission of disease, deserves a high priority.

Out of 454 respondents 248 (54.6 percent) suffered some deformity at the time of being interviewed by the investigator. It should also be mentioned here that a large number of cases without any deformity at the time of commencement of treatment became deformed by the time of completion of treatment.

A leprosy patient has to face many difficulties if he/she is labelled as a leprosy sufferer by the society. These problems are categorized as individual, familial and societal. Among the individual and familial problems stigma and ostracism are the most important ones. Due to this, leprosy patients try to conceal their disease from the society till the disease becomes visible to all.

A majority of the young unmarried leprosy patients have found it difficult to get married. We have found that 23.3 percent of the deformed patients attributed leprosy as the only reason for not getting a partner for marriage. Moreover, 27.3 percent of the respondents found it difficult for young unmarried members in their families to get married. Marriage life of a small number of married respondents is also adversely affected. We have found that 42 (9.3 percent) deformed (married) patients whose disease is apparently visible are treated badly and are felt unwanted by their families and relatives.

Apart from these problems economic constraints arising out of the physical and social condition due to leprosy also affect the leprosy patients, more so in case of those who suffer deformities/disabilities.

Among the deformed patients, 18.3 percent of the respondents who were working before the onset of the disease lost the job due to deformity, 20.9 percent left the job and 5.9 percent changed their job voluntarily. In
addition to an increase in the number of patients in the 'no work' category after deformity, there has been a drastic fall in the number of cases who found work for reasonable number of days in a year after the disease/deformity, compared with their pre-impairment position. 63 percent of the total sample faced unemployment problem occasionally or permanently from the onset of deformity. It should be noted that among the patients who have been earning after disease/deformity it is in the low earnings groups that deformity cut deeply into their earnings potential.

The deformity due to leprosy constricts the ability of the patient to engage in productive economic activity resulting in substantial productivity loss. Apart from this direct loss, the social stigma under which the patient is subjected to isolation and agony also contributes to economic loss. The longer the treatment period, the higher the costs in terms of both treatment-related expenses borne by the patients and the relatives and productivity loss. The new therapy regimen of multidrug has considerably reduced the length of the treatment period cutting into the total costs as compared with the earlier monodrug therapy. Our economic evaluation has thus mainly dealt with the above two aspects (i) estimating the productivity loss due to deformity and (ii) evaluating the cost-effectiveness of the two drug regimens.

The productivity loss due to deformity has been estimated in the framework of a logistic model and an earnings model applied to 454 sample patients. Using the logistic model we have derived the probability of gainful employment associated with each of the patients, given the patient-specific attributes. From the earnings model applied only to the gainfully employed patients we have derived their expected earnings given the same patient-specific attributes as used in the logistic model. The product of the employment probability and the corresponding estimated average earnings of the gainfully
employed gives an estimate of the expected earnings of the sample patients given the particular attributes. Applying the same methodology under the assumption that the patients were cured of deformity we have estimated the potential earnings of the sample patients, i.e., what they could earn if they were free of deformity. The differential between the two, the earnings with deformity and those without deformity is the estimate of the productivity loss due to deformity.

Due to minimal facial and eye deformity, these two cases have not been considered in the models. As many as 248 of the sample patients are feet-deformed, a majority of them being hand-deformed also. Both the deformities have been found to affect inversely the employment probability and the earnings almost by the same degree. Social stigma also suppresses the probability and the earnings. The substantial differential found in the employment probability and the expected earnings between the sample male and female patients in the same categories is noteworthy.

Next, we have proposed a fundamentally different concept of cost-effectiveness rate defined in terms of the estimated productivity loss and the potential earnings. The effectiveness-cost ratios have been estimated over the entire sample on the basis of the earlier logistic and earnings model results, and these have then been analyzed against a set of explanatory variables including the treatment related costs, mode of the treatment, patients’ perspectives and deformity grades. The effectiveness-cost ratio has been found to decline rapidly with increasing deformity grades and to rise modestly with treatment-related costs. Multi-drug regimen-compared with mono-drug one as well as regularity in taking treatment (the right perspective of the patients) contributes positively to the effectiveness-cost rate. A series of sensitivity tests under different conditions then follows.
The objective of comparing the two drug regimens has well been met in the framework of all the models. The results of both the logistic and the earnings as well as of the sensitivity model of the effectiveness-cost ratio are all in favour of multi-drug therapy rather than mono-drug therapy. The employment probability and the expected earnings of the patients under multi-drug therapy are higher than under mono-drug therapy, and hence the relative productivity loss associated with patients under mono-drug therapy is also higher, implying a lower effectiveness-cost ratio. A change over from monodrug therapy to multi-drug therapy considerably raises the effectiveness-cost ratio in the framework of the sensitivity model.

This research piece has thrown very valuable information on the economic evaluation of leprosy control in India. Very few studies are available that too done by social scientists on socio-economic aspects of leprosy. In that respect, the researcher hopes that this work fills the vacuum in this area.

Cost-effectiveness studies of (i) Leprosy control through primary health care, (ii) Preventing deformities in leprosy, (iii) Community based rehabilitation (CBR), could be the areas for further research.