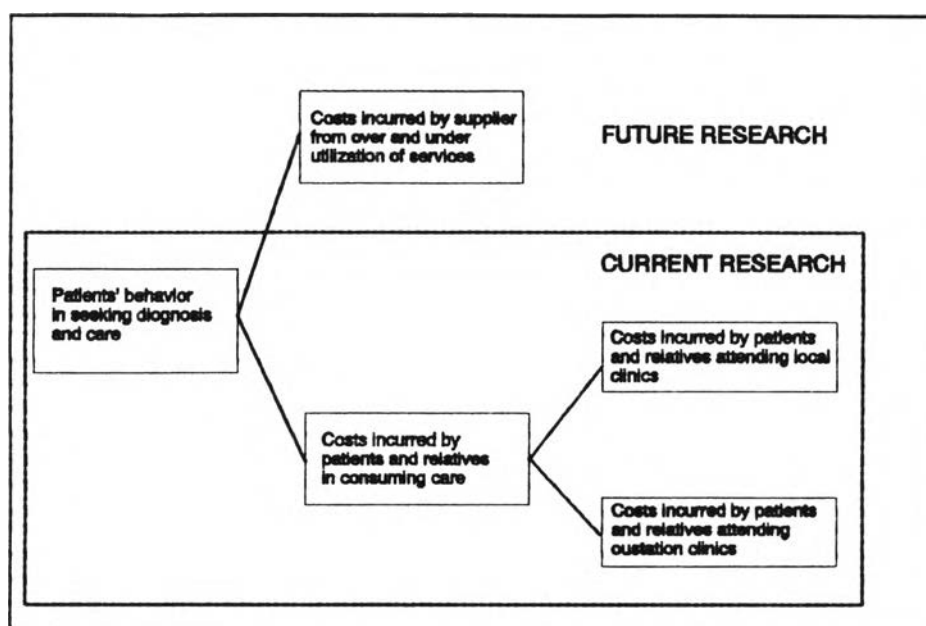


CHAPTER 2

THE RESEARCH FRAMEWORK

The broad concerns of the research are presented in Figure 2.1. The current focus is the costs incurred by patients and their relatives when patients seek leprosy diagnosis and treatment from outstation as compared with local clinics.

Figure 2.1 Framework of the research

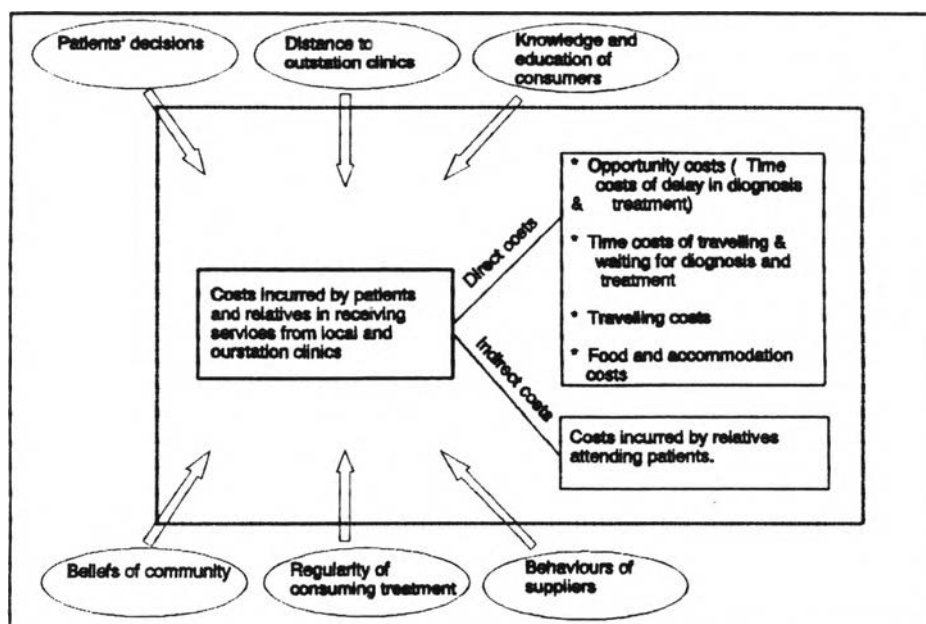


Patients may incur costs in seeking diagnosis and treatment from other sources and services prior to the current service point. Such costs are not included in this study. Suppliers (service providers) also incur costs in providing services and additional costs due to over or under utilization of those services. These costs while clearly important in determining the strategy of control are not included in this study.

There are many factors affecting patients' behaviors and therefore costs incurred by patients such as distance from home to service points, knowledge and education of patients, beliefs of patients and the community, regularity in consuming treatment and the behavior of suppliers. All of these factors are assumed to be constant under the defined time period of the cross sectional study.

The costs to be determined in this study are the costs to patients and attendant relatives when they seek diagnosis and treatment at an outstation rather than the nearer local clinics as shown in Figure 2.2.

Figure 2.2 Components in Determining Costs Incurred by Patients



2.1 Principles of Decision Trees

The first objective of this study is to explore alternative practices of leprosy patients in seeking initial diagnosis and in their response after initial diagnosis and/or treatment. For this purpose it is necessary to use the principles of a decision tree.

A decision tree is a graphical method of expressing, for the decision maker, in a chronological order the alternative actions available and the alternative events (uncontrollable factors) involved in each action by chance

There are four major steps in the process; analysis of the system and detailing of data, construction of a decision tree using graphical symbols, checking the tree structure and then making the analysis and obtaining solutions

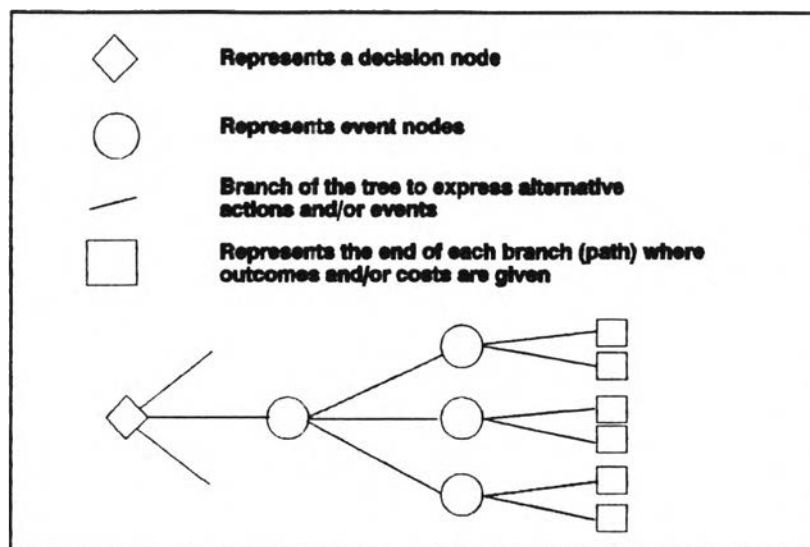
In analysis of the system and detailing data it is necessary to:

1. Identify the decisions to be made at each stage
2. Identify the alternative actions at each decision stage
3. Identify the alternative events for each action
4. Determine the chance (probability) of each event happening
5. Identify the outcome/cost as a result of each alternative path of action and event

It is assumed, in the construction of a decision tree that alternative actions are known (given), alternative events and probabilities of occurrence are known (given) and outcomes and costs of each alternative are known (given)

Special symbols are used, in the construction of decision trees, as shown in Figure 2.3

Figure 2.3 Symbol Conventions Used in Constructing Decision Trees



The detailed steps in construction are:

1. Write in the first decision node
2. Immediately after the first decision node, add the alternative actions (branches of the tree)
3. At the end of each branch add the event node
4. After each event node put the alternative events (branches) and chance of occurrence
5. After each branch of the events put the second decision node (if any) and repeat 1 to 4 if there are more events or indicate an outcome/cost box if at the end of the branch.

On completion of the tree it is necessary to check completeness. Check that all alternative actions and events are included in the tree, check that the nature and sequence of decisions is correct, check the probability (chance of occurrence) of each event, check the figures of outcome/cost at the end of each branch of the tree and prepare a calculation table for each branch of the tree

In this study, the decision tree can illustrate all possible options for leprosy patients in seeking diagnosis and treatment. The behavior patterns of patients can then be summarized. The behavior patterns reflect the costs to be incurred by patients prior to and after the current diagnosis and treatment.

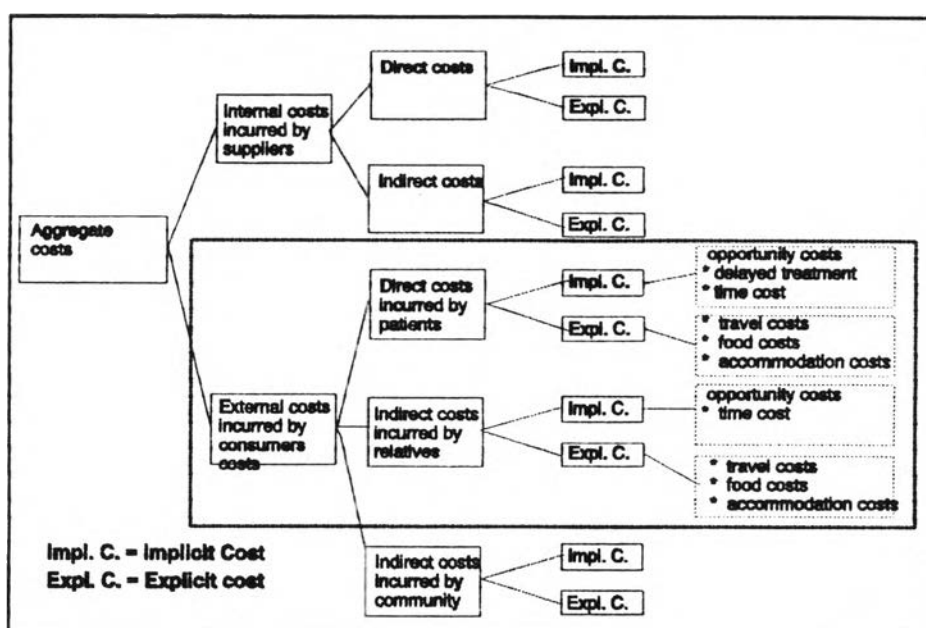
This research is only concerned with the costs to be incurred by patients and accompanying relatives in seeking diagnosis and treatment at current service points and makes no analysis of the actions which may have been taken previously.

2.2 Principles of Costing

Objective 2, (section 1.4), is to develop methods for determining costs incurred by patients and relatives and potential cost saving for leprosy patients if they attend at local clinics. This section explains the types of costs required to achieve objective 2.

The aggregate framework of costs is presented in Figure 2.4. The costs of concern in this study are shown within the boxed frame.

Figure 2.4 Aggregate Framework of Costs



Internal costs

- * Costs incurred by the supply organization in producing and/or distributing goods and services

External costs

- * Costs incurred by other parties outside the supply organization. For this particular case the external costs are costs incurred by patients and attendant relatives when patients seek diagnosis and treatment at leprosy clinics. There may be other external costs incurred by patients i.e. the costs of home care for some patients but such costs are not included in this study

Costs to be incurred by suppliers and patients in diagnosis and treatment are direct costs since they are directly to the activity. The direct costs incurred by patients in seeking diagnosis and treatment may include travel, food, accommodation costs and the opportunity costs.

Opportunity costs are implicit costs since they are not expended but rather the revenue forgone as a result of the activity of

seeking care. Opportunity costs have to be estimated and included in the economic costs of the activity.

Two components of opportunity costs which are important in this study are the opportunity cost due to the delay in seeking initial diagnosis and treatment and the time cost in seeking diagnosis and treatment.

The delay between the onset of symptoms and seeking diagnosis and treatment cause patients to incur costs in two aspects; (1) the disease may progress and patients may develop deformities. This could lead to limitations on activities, loss of jobs and social stigma. (2) late diagnosis and treatment may mean a delay in recovery and will often result in further transmission. This additional transmission will result in an additional cost being incurred by the community. The costs incurred by the community are not included in this study.

Costs incurred by relatives accompanying patients to the leprosy clinics are considered to be indirect costs since they are not direct to the activity (diagnosis and treatment). The costs incurred by accompanying relatives can be both explicit (costs of travel, food and accommodation) and implicit (time costs).

Magnitude and components of costs incurred by patients and accompanying relatives in seeking diagnosis and treatment at local clinics is compared to the costs incurred if they attend outstation clinics, that is, outside their district.

2.3 Literature Review

In reviewing the prior work, relating to the research, there are four questions of concern:

1. What is known about the behavior and determinants of behavior when leprosy patients seek diagnosis and treatment?
2. What is known about the costs incurred by leprosy patients in seeking care?
3. What, if any actions have been taken to change health care consumption behavior and to reduce the costs to patients? What has been the outcome of such actions?

2.3.1 Behavior in Seeking Diagnosis and Treatment.

Leprosy control programmes throughout the world emphasize early diagnosis and regular treatment as the only way to reduce the probability of debilitating deformities and transmission of the disease (WHO). However, in practice, the actions of those afflicted, frequently among the poor and uneducated (Noordeen 1985), may be driven more by social and economic fears and uncertainties rather than the apparent logic of the informed medical professional.

Leprosy has generally been associated with poverty and crowding may facilitate transmission (Noordeen 1985). Economic development has been proposed as a reason for the decline of leprosy prevalence in Europe and Japan. Consistent with this hypothesis is the twenty year lag in the decline of leprosy (relative to the country) that was observed in the Okinawa prefecture in Japan. This prefecture had the slowest rate of economic development in the country. These shifts in the risk factors appear to occur independent of any leprosy control activity, because they have been observed in countries with strict or relaxed isolation policies and in the absence of any control measures. Once the situation is reached in which each new lepromatous case fails to produce, on average, one new secondary lepromatous case, the disease incidence will gradually decline and ultimately reach zero (WHO 1985b). This process has important implications for leprosy intervention programs in endemic areas.

While poverty increases vulnerability to disease, it restricts at the same time the access to health facilities. At present health resources are not shared equally by all the people, significant gaps still exist and health is the privilege of the few. It has also been observed that the poor and uneducated people are the least knowledgeable about the early signs and symptoms of the disease.

The World Health Organization rightly insists that the indicators for monitoring progress towards Health for all by the year 2000 should reflect progress in correcting this imbalance and closing the gap between those who have access to health care and those who do not. The International Conference on Primary Health Care (1978) declared in clear terms : "The existing gross inequality in the health status of the people, particularly between developed and developing countries as well as within countries is politically, socially, and economically unacceptable and is therefore common concern to all countries. The promotion and protection of health of the people is essential to sustained economic and social development and contributes to a better quality of life and to world peace."

Patients having better economic status do not desire to make known their disease to the local community. If and when treatment is needed they often seek care privately or at outstation leprosy clinics.

It is observed in India that leprosy patients who ascribed the disease to spirit or witchcraft viewed treatment as temporary relief rather than a cure. Consequently, regular attendance for the treatment was not a priority for these patients. However, as deformities arise the patients do seek treatment. Hence visits to the outstation leprosy clinic become more frequent. In Nepal also traditional belief has played a vital role, specially in the rural and remote areas. The existence of an old belief and superstition about the disease as a past sin has presented the people with a dilemma. With the fear of social disgrace patients have to change their behavior, give false addresses and look to alternative practices for the treatment from outstation leprosy clinics.

Treatment of locally endemic disease was one of the goals set for primary health care by the World Health Organization at the 1978 Conference in Alma Ata. As a result of this recommendation, some vertical leprosy control programmes were dismantled in favor of integration of leprosy control into primary health care programme. The expectation was that with more personnel working in leprosy control, case finding would improve. In practice, the reverse can occur where staff are not trained and not committed to leprosy care.

In the treatment of leprosy and dealing with the patients the behavior of the supplier is an important determinant of the patient's consumption of health care. When paramedical workers are regular in conducting clinics and patients are treated with respect they become regular in treatment.

Strong evidence still exists that patients - new and old - still prefer not to divulge the fact that they are under treatment for leprosy and even adopt the ruse of giving false accommodation addresses in order to avoid divulging their real place of residence (Josua et al.1983). There is therefore a tremendous obligation on the part of officers concerned to be very discreet and tactful in handling leprosy patients they are investigating."

2.2.2. Costs Incurred by Patients

Some writers (Bijleveld et al.1977) who have examined the costs of leprosy control but have not considered the costs incurred by patients. But costs can be incurred in a number of ways.

It is observed in India that the age-old social stigma attached to the disease may lead to broken homes which adds to the problems and misery of the patients (Max 1986). It is argued that the spectrum of losses due to leprosy cannot be easily quantified. Since the disease causes social and economic consequences to the patients, their families, their communities and ultimately to the nation, economic aspects of the disease and the implications thereof to the patients should be a subject of concern.

In early days in Nepal leprosy patients were kept and treated in the leprosarium. Once entered into the leprosarium they were restricted from leaving. The patients who could work and generate income had to stop their work, so there was a considerable economic loss to the patients and their families.

Actual costs incurred by the patients for the treatment is difficult to quantify. Generally leprosy patients do not tell the correct details about their disease. When they do not feel better getting the treatment from the clinic they again change the treatment center and try to conceal the previous treatment history. So, with this behavior it is not an easy task to study costs incurred by the patients seeking leprosy care and treatment. Change of attendance at the clinic, moving from one to another hoping for better treatment results

in higher costs to the patients. These costs must be considered. But up until now this point has not been studied. Costs incurred by the patients depends on the level of clinics, the severity of disease, knowledge about the disease and the economic condition of the patients.

2.2.3. Reduction of Costs to The Patients

Some writers(Noordeen 1985) have commented on the economic condition of the leprosy patients. It has been accepted by many writers that leprosy patients are generally poor and under privileged groups. Patients need a long time to be cured. How long it takes to be free from the disease and by how much costs can be reduced to the patients for the treatment depends on the stage of the disease as well as the attitude of the patients.

Myo - Thet et al. (1992) analyzed the economic costs of leprosy. They concluded that elimination of deformity would raise the probability of gainful employment from 42.2 to 77.6 %. The author's extrapolation to an estimated 645,000 patients with deformity in India suggested that elimination of deformity would raise productivity by \$ 130 million per year. This amount is one-eleventh of India's entire official development assistance for all purposes from all sources in 1985 (\$ 1,470 million). The analysis did not consider the cost savings to patients if it was not necessary to consume leprosy health care. Reducing the cost of control has been discussed by many writers, but most have omitted the issue of cost reduction to patients which is a significant question. Unless efforts are made to reduce the costs of the patients, control costs will not be substantially reduced.