



CHAPTER 1

INTRODUCTION

Leprosy is a debilitating infectious disease which affects 1.17 per 1000 of the population in Nepal. The costs incurred by patients and the community in providing control and care is considerable. Actions to reduce costs as well as the rate of infection is therefore very important.

1.1 Nature of the Disease:

Leprosy, one of the oldest diseases known to mankind, is caused by Mycobacterium leprae. It affects the cooler part of the body skin, notably the upper respiratory tract, anterior structures of the eyes, and superficial segments of peripheral nerves.

The signs and symptoms of the disease result from three interrelated processes, growth and dissemination of Mycobacterium lepra, host immune response and damage to nerves. The clinical course of leprosy varies from asymptomatic infection to severe disfigurement of many parts of the body.

Onset of leprosy is usually gradual, and the first signs may not be apparent for many months or years after infection. As the disease progresses, usually over several years, skin lesions appear, heal spontaneously and can become more frequent in reappearing. Skin lesions range from under-pigmented patches which are usually accompanied by loss of skin sensitivity, to multiple nodules with extensive skin thickening and folding. The disabilities caused by leprosy are mainly damaged limbs and eyes, and this affects not only the functioning of these parts of the body but also causes the loss of sensation. Disfigurement and the disabilities due to the disease lead to serious psychological, economic and social problems for patients and their families.

The exact mechanism for transmission is still not fully understood. Transmission may involve skin contact, but nasal discharge from multibacillary patients is considered to be a more important vehicle for spreading the infection. Not all persons infected with the leprosy bacillus develop the disease. Resistance or immune mechanisms in most people are able to prevent the occurrence of physical manifestations of the disease. If the disease becomes established and is not treated with the appropriate combination of drugs, the disease can cause progressive and permanent damage to skin, limbs and eyes. Loss of sensitivity in the skin often results in unnoticed burns or ulcers. Lesions of nerves can lead to muscle weakness and atrophy resulting in deformities especially of the feet and hands. Visible evidence of the disease often leads to intense social stigma and discrimination against patients.

Until the introduction of drug dapsone in the 1950s, leprosy control consisted mainly of isolating patients. It was believed that a leper could infect all people in the community. The introduction of dapsone enabled patients to be treated within the community. The treatment of leprosy with monotherapy using dapsone, which is a slow acting drug, acts mainly by stopping the bacteria from multiplying, rather than by killing them directly. As a result, long courses of treatment, often life long, were necessary. When this was combined with case detection and health education, a degree of success was possible.

However, after about 25 years, the disease became resistant to the drug and treatment became increasingly ineffective. This period of failure and frustration changed dramatically with the introduction of combinations of drugs, known as multi drug therapy (M.D.T.), the standard regimens of which were first recommended by a WHO Study Group in 1981. In MDT Rifampicin and Clofazimine, with different modes of action, are combined with dapsone.

Rifampicin is the most potent drug available, a single dose of 600 to 1500 mg. killing more than 90% of viable Mycobacterium lepra. One dose of MDT kills enough bacilli to make the patient non-infectious, while the same process takes one year with dapsone monotherapy. For the less serious forms of leprosy known as paucibacillary leprosy (PB), the treatment consists of administering a combination of rifampicin monthly and dapsone daily for six months. For the more serious forms of leprosy known as multibacillary leprosy (MB) the treatment consists of administering a combination of Rifampicin and Clofazimine monthly and a combination of Clofazimine and dapsone daily for at least two years or until the skin smear is negative.

Multidrug regimens serves four purposes. First, it interrupts the chain of transmission in the community by rendering infectious cases noninfectious. Second, it cures patients of the disease. Third, it affects drug-resistant strains. Last, it halts the disease process, and if the disease is treated in its early stage, it will prevent further development of deformity.

Multidrug therapy has led to significant changes in leprosy control. It led to the discharge numbers of individuals who had long been labeled as leprosy patients. In some countries a tenfold decrease in disease prevalence has occurred within 10 years.

1.2 Leprosy in Nepal

Leprosy continues to be one of the major health and social problems in Nepal. A pilot survey in collaboration with HMG/Nepal and WHO in 1961 yielded an estimate of 100,000 cases (L.C.P Nepal 1991).

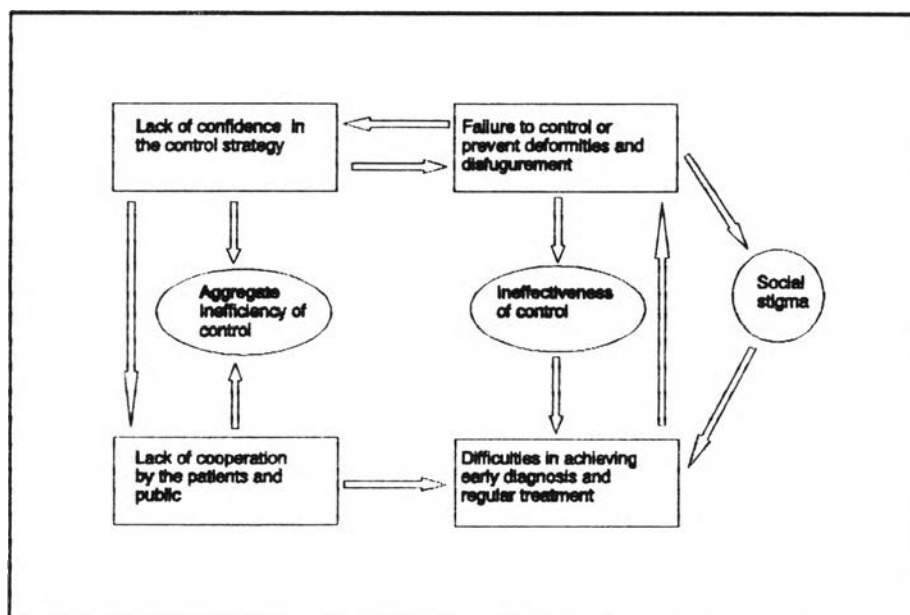
The distribution of cases in the Kingdom in 1994 is not uniform. A higher prevalence rate is observed in the central plain, in the hilly districts of the western and mid western regions and eastern plain region such as Sarlahi, Mahottari, Rautahat, Bara, Nawalparasi, Jumla,

Morang and Saptari. There are fewer cases (less than 1/1000) in the districts of the eastern region such as Ilam, Panchthar, Taplejung and Solu with no case reported in Rasuwa and Dolpa districts. The number of registered cases receiving treatment in March 1993 was 21,702 giving a national prevalence rate of 1.17/1000.

Despite considerable efforts by the control programme there has not been a significant reduction in prevalence rate over the past 6 years from 1987 to 1993. Progress in control continues to be hindered by the lack of efficient methods for early diagnosis and implementation of control and treatment measures. Diagnosis is still made on the same principles as a century ago (clinically and on histopathological findings).

There are many ideas as to the reasons for the high prevalence which may be described in terms of ineffectiveness and inefficiency in control. Factors contributing to these states are presented in Figure 1.1

Figure 1.1 Relationship among factors affecting prevention/control of leprosy



1.2.1 Ineffectiveness of Control

Ineffectiveness of control is reflected in the unchanged prevalence of leprosy and the proportion of new patients with severe disfigurements in the country. Ineffectiveness is thought to stem from the social stigma associated with the disease, coupled with patients reluctance to present themselves for care particularly (it is thought) at local service points where their condition may become known to neighbors. Delayed diagnosis and treatment allows for further transmission and more severe physical damage to some patients which

could be avoided given prompt treatment.

1.2.2 Inefficiency in Control

The existence of patients with severe disfigurement, whether due to late presentation, late diagnosis, in effectiveness of earlier drug treatments or poor patient compliance, erodes confidence in the effectiveness of treatment.

Cooperation and behavior of patients, once diagnosed, is also an important determinant of further transmission and the proportion of patients with severe impairments. Where confidence is lacking patients may become irregular in taking their drugs. The expectation of no cure then becomes self fulfilling because of their own behavior.

But inefficiency in control is not simply the product of patients behavior. There is a general lack of interest, on the part of many medical doctors, in leprosy work. The attitude of health care workers to those infected can also be a major determinant of the compliance of patients and the willingness of new patients to present themselves for care.

1.3 Leprosy Control System in Nepal

The Himalayan Kingdom of Nepal is a land-locked country of about 150,000 sq. km. with a population of 19.0 million (1993). The country is divided into three distinctive geographic regions, running east to west, mountains, hills and plain. The geography affects the population distribution and access between settlements.

The mountainous area, along the north of the country lies at an altitude varying from 4877 meters to 8848 meters above sea-level. The region includes the world's highest peak, Sagarmatha or Mount Everest (8848m). Because of the altitude and cold climate in this region, it is the most sparsely populated area.

The hilly region is located in the middle part of the country and runs from the east to west. Altitude varies between about 600 to 5000 meters above the sea level. This type of terrain occupies the largest part of the country with about 10% of its area suitable for cultivation.

The plain (terrain) region, which extends from east to west along the southern side of the country, is an extension of the Gangetic plains of India. This region provides most of the fertile land and dense forest of the country. Forty percent of this land area is under cultivation. In the 1981 census, 43% of the population lived in this area. Although the population of this region was smaller than that of the Hill region, it is increasing at a rapid rate.

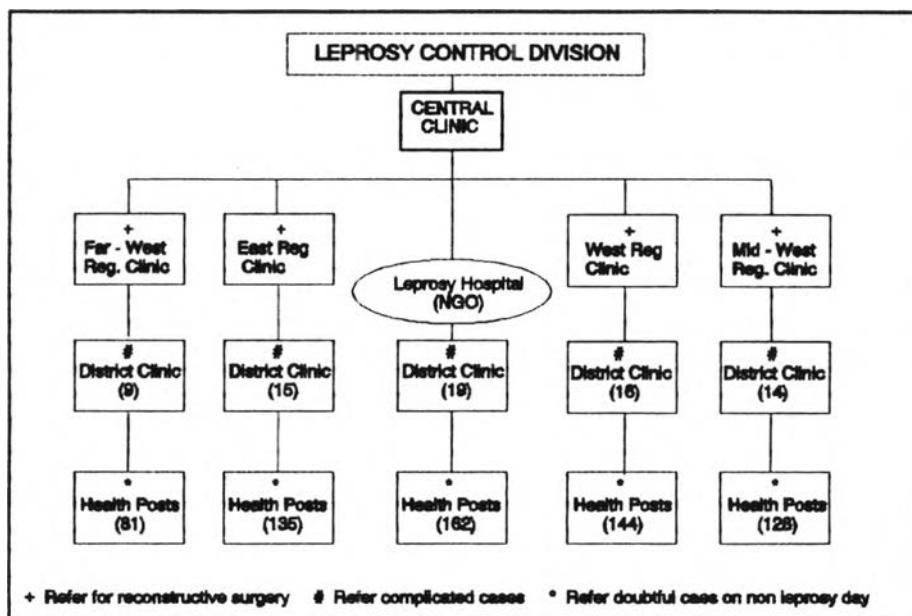
Administratively the country is divided into five development regions, 14 zones, and 75 districts. Leprosy services are available in all the leprosy prevalent districts through health posts and regional

clinics (Figure 1.2). Generally a leprosy worker conducts a leprosy clinic at each health post on one day in each month. Where the patients are very few and the cases are only on monotherapy treatment, basic health workers conduct the leprosy clinics under the supervision of leprosy supervisors.

In each district there are at least two leprosy workers including leprosy supervisors and senior paramedical workers to conduct the clinics and follow up of the patients in the districts. These staff also give refresher training to basic health workers at the health post and village health workers. Treatment services and drugs are available free of charge through - out the country. Clinic days are fixed and made known to the public through the health institutions.

Suspected cases found in the non leprosy clinic days in the health post levels are referred to district leprosy clinic or to other clinics where patients can be diagnosed and treated. After the diagnosis if the case is positive first dose of treatment is started and patients are given drugs for one month and then are referred back to their nearby local leprosy clinic to receive further treatment. Patients are referred to the district, regional or central clinic according to the severity and nature of the disease. For reconstructive surgery patients are referred to the leprosy hospital.

Figure 1.2 Leprosy control system in Nepal



1.4 The Problem and Rationale.

It is observed that many patients receive diagnosis and treatment from outstation clinics, that is at a clinic away from their local clinic. They may seek care at another health post within the district, travel to the regional clinic or travel to a clinic in another region.

The causes are thought to be:

- * social stigma makes many patients seek diagnosis and treatment where they are not known.
- * where patients interrupt drug therapy consumed at a local clinic, some feel ashamed to go back and prefer to re register at another clinic.
- * some patients have limited confidence in local personnel and believe Regional/Central clinics will provide more effective service.
- * where diagnosis is not immediately available on non leprosy days at a local health post some patients may go to outstation clinics.

The location of the clinic visited by each patient will determine the costs they incur in consuming treatment. It has been suggested that the extent of this travel to outstations places a considerable financial burden on many patients, in relation to daily wage rate and adds a significant additional cost to the costs of treatment (aggregate cost). If extensive use is made of outstations, this could also lead to a under utilization of some facilities and over utilization of others.

Whether this is a significant problem has first to be determined. Then consideration can be given to actions which could/ should be taken. The purpose of this study is therefore methodological and operational. Methodological to examine how costs could be determined, and operational, to assess the magnitude of the additional costs incurred by leprosy patients who go to an outstation clinics rather than going to their local leprosy clinic.

1.5 Objectives of the Research:

Given the situation described above the specific objectives of the research are:

1. To examine alternative practices of leprosy patients in seeking leprosy care.
2. To develop methods for determining costs incurred by patients and their relatives in attending outstation clinics and the potential cost savings for leprosy patients if attending at local clinics.
3. To examine the implications of potential cost savings on policy options for leprosy care services.