

# 1. Introduction

## 1.1. Background

Most of the areas where leprosy is found today, belong to developing countries. Concurrent with an increasing awareness of the public health problems in these countries in general, the necessity of solving the leprosy problem has become more and more apparent. Primary prevention represents the only satisfactory solution to the problem, and primary prevention has to be based on epidemiological knowledge. However, the epidemiology of leprosy is still only known to some extent. Apparently, *M. leprae* is a necessary but not sufficient factor. To assess the significance of other factors, such as standard of living in general, specific environmental factors and genetic factors, has been most difficult.

This lack of knowledge has several causes. Traditionally, leprosy has been considered to be a disease of the underprivileged, and limited resources have been available to investigate and combat the disease. Furthermore, the study of the epidemiology of leprosy represents a difficult task; accurate knowledge of all cases and of the population at risk is hard to obtain in areas where leprosy is most frequent today (Lechat, 1973).

Epidemiological studies of leprosy will not only require money and manpower. Due to the considerable incubation period, long periods of observation are also required. This is particularly the case when control measures are to be assessed. There is, therefore, a special need to evaluate and utilize for epidemiological purposes, relevant data already gathered in medical files and registers.

In Norway in the middle of the last century, leprosy represented a considerable public health problem (Irgens, 1973). Information on the total population is at hand in general population censuses, from 1865 organized as nominative censuses. Detailed information on leprosy patients has been obtained through compulsory notification of all cases, enforced by a Royal Decree of 1856. Routines of central registration were carried into effect the same year (Irgens and Bjerkedal, 1973); routines which formed the basis for a central national patient registry. The material covers a period of high rates of the disease followed by a rapid decline. Today, the disease is almost eradicated. The epidemiological development is in detail documented through this National Leprosy Registry of Norway.

## 1.2. Purpose

In brief, the purpose was to present, from an epidemiological point of view, the complete story of leprosy in Norway from the middle of the last century until today, based on a prospective, 'historical', longitudinal study, utilizing routinely recorded data.

The considerable amount of data, conventionally represented in handwritten registers, has, up to the present, made it impossible to utilize more than fragments of the total material in scientific studies. Accordingly, one aim of the study was, on the basis of all the material, and aided by EDP-techniques, to trace epidemiological features of leprosy in Norway in an attempt to clarify some aspects of the epidemiology of the disease in general.

However, from a general epidemiological point of view, the material of the study, based on a national patient registry established in the middle of the 19th century, was, in itself, quite extraordinary. Accordingly, a subsidiary aim of the study was to pinpoint technical and analytical questions related to the utilization of this source of data which, at the time of its establishment, represented a unique methodological innovation also involving important implications for today.

The organization of the fight against leprosy in Norway in general, and the establishment of the Leprosy Registry have been related in previous articles (Irgens, 1973; Irgens and Bjerkedal, 1973).

In the present study a computerized version of the registry provided information on leprosy cases. Special emphasis is placed on the *construction* of this version, transforming data to a representation compatible with computer techniques and transferring them from the conventional registers to a computer file. Likewise, an *evaluation* of the material with respect to its usefulness in epidemiological studies is related.

The material has been compiled describing time trends with respect to *geographical distribution*, and with respect to *age- and sex-specific incidence rates*, and *type index*.

Associations found to exist between mean age at onset, sex ratio and type index on one hand, and incidence rates on the other, have been used in an attempt to *predict incidence rates*. *Isolation* was the most radical preventive measure taken against the disease in Norway, and the effectiveness of the measure, in terms of lowered incidence rates, has been evaluated. Furthermore, the occurrence of leprosy among *relatives* has been analysed. In the district with the highest morbidity rates in Norway, the occurrence of leprosy at farm level has been compared with a set of *environmental variables*.

Each part of the results chapter ends with comments restricted to the particular subject, and in a final discussion the consistency of the findings with relevant hypotheses and current theories is considered.